

Pacient 1

Počet příspěvků:

36

Přispívá:

Pacient

Příspěvky:

1. (7. březen 2022) Good morning! Don't forget to smile and laugh. Enjoy your day today the weather is starting to pick up. Spring is near! Remember to love your family and hold them tight. Thank God for all of your blessings and put down your cell phone to hear what you might be missing.#rockinals #tamuraisadventure + *fotografie*

2a. (3. březen 2022) I have seven more days before my surgery. This surgery is life-threatening due to my weakness. Either way I am prepared and hoping I wake up with a smile and see my family in front of me. However I look forward to the moment that I see Jesus and no longer hurt.

Things I would leave with all of you is never give up hope. Put God first pray to him, tithe, thank him for all the blessings. Second your family hold them close, capture all the memories even if it's photos better than most silly and unattractive. Those are the ones that create the most memories. Make videos, back up those backups and revisit them often.

Whatever happens on Thursday is meant to be. I am okay with this I am sad how my family may feel whether I am gone or the difficulty they have agreed to fight to keep me alive. It takes a village. Always ask for help. Never be too proud. Always smile and laugh it just makes you feel better.

2b. If I don't wake up here on earth I pray that my legacy continues and all the hard work has not been swept on the the rug. That people remember I wasn't doing it just for me I was doing it for everyone in my situation or similar situation. I pray that they continue making ripples and spreading awareness.

When I do wake up it's going to be quiet for a little while. I haven't done a very good job practicing my eye gaze. My tick tock account has exploded and I get about 500 comments an hour. It's amazing when you ask your husband to be the voice ☺ for those who have my phone number thank you for always checking on me. Something I'm not used to because I've always been the person to check on you. Thank you for always being there and my support and please don't stop. It's easier for me to answer it the phone or text than me trying to thumb in a phone number and hit send. As far as how I'm feeling I still feel very weak and then lots of discomfort but that's to be expected. ALS is not an easy disease. I haven't been out of my bed for about 2 months except for a couple of hospital visits. I am on the phone 6 hours a day with doctors and lawyers trying to organize my care.

So the countdown begins! Either way I feel like I'm in a win-win situation. More time with my family to create more memories and chaos or more time with God.

#rockinALS + video a 2 fotografie

3. (27. únor 2022) Attended church with these guys and the guy behind the camera ☺ taking a very little low key day. So weak every time I am moved. Thank you for all the encouragement, snow angels, and sharing your adventures They have brought such a huge smile to my face! David would say sometimes even tears of joy with the hash mark on the wall before how many times I cried.

Don't forget to laugh and smile. Thank God for another day.

#rockinALS #tamuraisadventure + fotografie

4. (23. únor 2022) So many numbers in my mind
8593 days since I married my best friend
858 days since I was diagnosed with ALS
518 days since my last step
492 days since I accepted Jesus in my life
53 days since we saw our oldest boy
41 days since I lost an important part of my life, my father in law
40 days since we had a caregiver
39 days since we saw our youngest boy
16 more days until I get to breathe better
6 more days until I turn 46
My days are not done yet! I plan on adding so much to my life. Everything
flies by so quickly but for me I live one day at a time.
Thank you God for every day 🙏🙏
#rockinALS #tamuraisadventure +7 fotografií

5a. (20. únor 2022) Yesterday it took until almost 2:00 p.m. and a shower
when I realized was starting to feel better. I'm still not out of the woods
but David has been doing so good about making sure I do not miss any
fluids or medication.
I was planning on staying in bed all day yesterday but after the shower I
was feeling somewhat normal. So David and I went to on a date to the
movie theater. We caught the 3:00 and saw the movie uncharted. It was a
wonderful adventure movie with Matt Damon and Tom Holland. After the
movie was over David said would you like to do a second movie? I thought
about it I assessed my situation and his. How we were feeling. We were
like two little teenagers left in a movie theater. So we stayed for dinner, I
took my medicine, hooked me up with more formula and water. We
stayed in the lobby until 7:00 it was about an hour and a half. Then we
went and watched the movie dog with Channing Tatum. What a
wonderful movie highlighting such a hero.

5b. We didn't even go to bed until 10:00 last night and now we are up and getting ready to head to church. I Thank God for another day to create memories with my husband. We are going to fight this dehydration with a no questions asked kind of situation. We are going to fight his back pain and together we are going to be so strong. The laughter that has filled this house in the past 2 days has been so wonderful and relieving I don't know the rest of the day but I do know I am looking forward to church and thanking God for helping me get through all of these difficult moments.

We even started eye gaze training for David yesterday so that he knew how to operate it when I'm unable to help. I even trained him on how to use my Snapchat lol. Don't be surprised if you get silly videos from him ☺ I hope everybody has a blessed day today, don't forget to laugh, smile and enjoy every moment you have with those that you love.
#rockinALS #tamuraisadventure +3 fotografie

6. (13. únor 2022) Oh how I've missed you guys! I'm sorry I have not been posting this often in this group. Here is an update on my past 2 months. Although my fitness pal maybe super excited about my weight I am not. If I was walking and healthy I would be jumping for joy. Don't worry this is a positive post but my weigh in was 164. Between the stress, anxiety, depression, not wanting to eat, and dehydration I have put myself in a dangerous situation. 20 lb in 2 months. Yes I am working with a medical professional. No I do not want to go to the hospital and do not plan on it unless this does not turn around over the weekend.

Yes I am feeling better today! So much better that I am headed to church ♥ I am still fairly weak but I miss going to church. David and I are going to get out of this bedroom and out of this house and that my friends is the plan.

We got this! God is good I'm not giving up at all no matter what!
#rockinALS #tamuraisadventure +3 fotografie a 1 video

7. (6. únor 2022) Even if David and I are at home in bed. I can see the sun shining through my window. Yes I have been down for about a week but sometimes taking care of those that take care of you is so important. I really wanted to make sure my husband takes some down time for himself and gets a little relief in his back.

I don't know what it's like to be in his shoes but from my point of view I can tell that when you were responsible for the person that is unable to do anything for them themselves and you're not well it makes everything 10 times harder.

I would rather lay beside him and hold his hand than want him being pain. Thank you God for the sun shining through my windows, for another day with my husband and for all the four-legged buddies in our bed.

#rockinALS +2 fotografie

8a. (4. únor 2022) So many people are sad when they read this. Please know I'm excited that I will be able to breathe. I am aware of the risks that are very high. If I survive the surgery I'll come out with a smile. If I do not then I will be in heaven watching over all of you knowing that my purpose was done here.

So why not come up with an extra plan. So far this month has been a blessing. On the first of February I get to meet my awesome surgeon. On the second of February David and I had a spa day. On the 3rd of February I got to spend time with my middle son and go to special visit from Merla Roy who spoiled us with cookies and some beautiful flowers. Today I get to spend the day with Grammy watching our favorite cooking show.

Now the next part I am going to talk about I know in the comments I will get disagreements. Please know that I do understand the other portion but I am very confident that my body will disagree. When I wake up with a smile from surgery I will no longer be able to communicate with my voice. This surgery is permanent, yes we could deflate the cuff just enough so that air could pass over my vocal cords but if I'm already having a difficult time talking and it uses so much energy why would I want to use more? The same goes with eating I already have a difficult time getting food caught. We could deflate the cuff So that I could eat but again it will use so much energy and I already have a hard time with this now so why risk it.

8b. This doesn't mean I'm giving up but I am trying to be very realistic. I am embracing the surgery with open arms and so grateful that I will be able to breathe better. Now for the list of food choices that I want to get out of the way. I still eat but in small quantities as I stated before food gets stuck. I still try to enjoy every bite. I figured why not have a few of my favorites before A favorite treat is the chocolate frozen yogurt at Sam's club. Definitely going to have to have some of that. I would say a whole lobster but I could never eat the whole thing and my husband is not a huge fan so why not lobster tail.

A very well cooked steak like melt in your mouth steak.

I would say nachos but I have so much nacho cheese here I think David has that part covered ☺ As far as any other food maybe one last trip to Tuscan bistro for their fried calamari the best ever. Now for my voice If I ever have the chance to talk to Steven Tyler, Keith Urban, to see my best friend Jessica one more time in person, just silly little things like that.

Spending the last 30 days with my husband and talking his ear off. Wait I already do that lol. The list is huge and kind of out there but I think that just being able to talk about it would be wonderful. The final thing would be just know That David promised if I woke up and survived this thing we're not just going to stay home. We are getting out of the house It won't be easy but we're going to do it so the real bucket list is not changing. +2 *fotografie*

9. (3. únor 2022) Did you know that healthy adult lungs capacity is 6 liters? I am currently at 1.30 liters. Talking uses so much energy but I just want to keep talking. I'm grateful that I have been able to prolong the process until now. I will be almost 1.5 years since I had to decide if I wanted a tracheostomy or not. I struggled with how my family felt thinking I was being selfish. Last August I was able to share my fears with my family and learned that they are here for me no matter what. I can honestly say I needed to hear that from them.

So I am going to move forward with them right by my side. I am ready to move forward and look forward to breathing easy. I have been thinking of my new fashion and how I can make it look fabulous 😊

This will be my new favorite accessory. Bringing the choker and ascot style back. +*fotografie*

10. (1. únor 2022) Step one is now complete! Today they stuck a camera in my nose and down my throat to view the airways. the doctor said I had a beautiful airway perfect for my tracheostomy. All the paperwork has been signed and risks have been discussed.

Step two is to wait for the surgical team to call with a date We are scheduling approximately 3 -4 weeks out.

We're still looking for a caregiver we have interviewed and waiting for paperwork to return.

The process for the surgery I will be there Minimum 7 days but it could be a little longer due to My blood clot history and having to wean off of the medication for the surgery.

There will be a second surgery scheduled after this one for the port that will help provide nutrition and hydration.

Overall I get to add a new doctor to my collection and so far the sun has warmed the day up. Today has been a great day.

Don't forget to smile and laugh!

#tamuraisadventure +3 *fotografie*

11. (29. leden 2022) My son shared this with me this afternoon and it sure did get a chuckle out of me. I hope everyone is all bundled up safe and warm. We have some great drifts for some snow angels tomorrow!

If you don't have snow it's okay because any angel is accepted. I've seen sand angels and paper angels. We've even made angels out of packing peanuts on the floor.

Don't forget to smile and laugh today. Hold your loved ones close ?

I plan on doing mine tomorrow hopefully. I may not be able to move but my husband can help me with my hooyer It will be a little painful but it'll be well worth the laughter and smiles.

#snowangelsfortammy #rockinALS +video

12. (27. leden 2022) From Georgia to Maine this weekend We are going to get what they call " the bomb ". This means snow for everyone! I can't wait to see all the snow angels. Don't forget to tag me ☺ use #snowangelsfortammy ❤️ Don't forget to smile and laugh today! #rockinALS #tamuraisadventure +2 *fotografie*

13. (22. leden 2022) Today I had my pulmonary function test. I may have not done the greatest but I can say that I had a very successful day with my sister-in-law. One day at a time it's all we can do and enjoy every second of every moment in that day. Today we had great memories and we were able to look back on some good old ones as well. I hope every one of you had a wonderful memorable day as well . Just don't forget to laugh, smile and thank God for every day you have with your family. #tamuraisadventure #rockinALS +fotografie

14. (18. leden 2022) I am so thankful for northern light home care, my nurse Leah, and coastal med tech Kate and Elizabeth. They have been so supportive during this whole crazy month of trying to prepare for a surgery that will be delayed. Please continue to pray that my pulmonary function test is absolutely amazing on Friday. That way we can delay the surgery even more.

I have low SPO2 and a high blood pressure. Completely understandable right. But I'm still smiling! Below is Parker and Dan my boys yesterday just before I had to say goodbye to Parker. I'm just missing my oldest Tyler who is traveling right now for work. I love them so much, these crazy boys have been so helpful and learning as much as they can about my disease. Off to watch my movie with Debbie and cuddle with Emma and the cats. Thank you for keeping my family in your prayers. Thank you to the American Red Cross for getting our marine home quickly. I wish I didn't have to return him though!

#rockinALS #tamuraisadventure +fotografie

15. (10. leden 2022) It's stretch time!

If you're reading this then take a moment to stretch. Self-care is so important and just a little stretch feels so good. It helps get your blood flow moving and wakes you up. Take your arm and put it behind your neck actually it would be your hand behind your neck then take your other hand put it behind your head and grab your elbow. Gently pull not so that it hurts really bad but just enough to feel the stretch. Now hold Do both sides. Now shake it off. Then rotate your head counterclockwise slowly. Do this five times each direction. Don't have time you do I promise it's only if you minutes and you could do it at work. Now pick up one leg while you're standing and pull your foot towards the front of you feel the stretch be careful you might lose your balance. Do both sides remember just stretch no pain. Now slowly try and touch those toes and back up only holding just a little while. Today I thought about the importance of stretch time even for those of us that are unable to move just gentle stretching to help move stiff bones and muscles. Today I have decided to start calling stretch time again but this time for my caregivers because it's so important to get that blood flowing. I used to do it at my old job's and everyone would start moaning and groaning but then laughing. So if you see my clock just take a second and stretch out or stretch your person out that's laying in bed or sitting in the chair. Let's get that blood flowing I hope you have a fantastic day today! #rockinALS #tamuraisadventure +fotografie

16. (9. leden 2022) Just out of reach.

this is me two years ago standing with a walker and of course walking slowly.

Today I depend on others to help me move. Placing the straw in my mouth, putting in the remote to my bed or my chair in a particular position. Having my cell phone just right or even the blanket in a special way..

The slightest distance would make me unable to use anything and sit and wait. The best way to describe it would be unable to reach something high in a cupboard. Or even being a little kid and having somebody hold something they wanted really really high in the air. Just enough out of reach so you wouldn't be able to use it without help.

I never thought that just a millimeter would make a huge difference.

So today's lesson is adjustment as necessary always ask for help even if it's just for a millimeter.

#tamuraisadventure #rockinALS +2 fotografie

17. (6. leden 2022) My husband came up with this idea We found the cart at a store here in Maine that's pretty popular. But I did find one online at Michaels how convenient. This holds my vent, my suction, my modem for my vent, the humidifier and the cough assist. He used a shower curtain rod on the side zip ties to hold everything. And special hooks that are holding the tubes in masks we use electrical tape. He also used a surge protector on the side of the cart that when plugged in will charge all components. This is been very useful with traveling.

I know a lot of you have been asking how to organize and I wanted to share.

For medical supplies he bought two shoe holders that hang on the back of the door and we have labeled them for easy access for my home nurses when they come. Those he bought at Target typically \$10 each but when you go to the CVS pharmacy here they give you a \$5 coupon every time with your prescriptions so in total we spend \$10. Below are the photos.

The best thing about all of this is everything is hidden so if you were to walk into my home you would feel at home instead of feeling like you're in a hospital. #rockinALS #tamuraisadventure +4 fotografie a odkaz

18. (1. leden 2022) I started a list of changes on January 1st 2021. Today I decided that my list should be much different as the changes looked scary. I decided to list what I am grateful for instead of the negative. I'm alive. I survived challenges of health risks. I have my family. My wheelchair has been upgraded I'm healthy. Went to my first concert in a wheelchair to see Brad Paisley. I can feel touch. I have a wonderful washer and dryer. We spent the summer traveling to 54 locations thanks to an awesome couple from Dirigo treasure hunt in Maine. I got to see our Marine in north Carolina. I have three wonderful caregivers. Met the singer songwriter of my song, 'Willow Tree' Mary Desmond. Went to an ALS concert starring Brandon Parsons and Jeff Neal also known as the drunken fiddler, as well as Ms Mary. Got my Covid vaccine fully and boosted. Watched Parker graduate boot camp. Was admitted to the hospital for a heart attack called broken heart syndrome and lived. I have witnessed God's blessings in person. The list is so much longer but look at the moments 🤔

Thank you for a wonderful year 🤔

Don't waste thinking about what you lost but what you gained.

#rockinALS #tamuraisadventure +2 fotografie

19. (17. prosinec 2021) Can you frog my legs?

Can you straighten my legs?

Can you put my braces on?

Can I push the button on my chair?

Can you turn my chair on?

I just ran out of water

I think my catheter is pinched

Alexa "did you just take your medicine?"

And repeat at least 20 times in the day

Help my arm is falling.

Can you please pick up my left arm and move it onto my stomach.

Can you please help me with my phone!

And repeat almost every hour on the hour at night when we should be sleeping.

Grateful for April today I've kept her pretty busy We have now successfully tried every piece of Tammy furniture today, Even the toilet... I think I just wanted to try the toilet just cuz.

#rockinALS +2 fotografie

20. (11. prosinec 2021) What's happening?

The generator will be installed just before Christmas by Lowe's Home Improvement .

The propane lines will be installed and attached to the house by David Pike contractor shortly after.

Then about a week after that the propane tanks four of them will be delivered by Fabian Oil .

Next week we will be having a video meeting with Northern lights head manager, coastal med tech, my attorney, my advocate, David and April. To discuss risks, surgery dates, training dates and more.

Things have been a little rough around my edges but with a little guidance I know that we got this. David has done so much to make sure everything goes just right. ♥

#rockinALS #tamuraisadventure #mylove +2 fotografie

21. (29. listopad 2022) By the year 2022 I will no longer be able to speak with the voice I was born with. Not due to surgery, due to progression.

I will have a machine breathing for me. I will have people driving my wheelchair for me. I feed through a hole in my stomach with a machine. Sometimes my husband hand feeds me too!

My home will be equipped with everything I need to be as comfortable as possible. My high risk status will need to taken seriously. No more random visitors.

Eyes on me 24 hours a day. Security cameras needed.

I feel like I am a human rag doll with pretty nails and healthy hair.

I will have no control of what I do except for what I say.

In 2022 I will be transformed into a bionic woman. Are you ready? I am!

It's not easy. I do cry, I hurt, I whine but I know I got this.

The great things for 2021 I will share soon as I have a running list.

Just know no matter what trust in the name of Jesus ♥ I got this! My mind and soul will stay strong.

#rockinALS #tamuraisadventure +2 fotografie

22. (26. listopad 2022) Generator scheduled for install ✓ Thank you David for making sure we will have a full powered warm house even if there is no power.

Adventure Van Is still in the shop but will be picked up tomorrow!
Sheepskin arrived from an anonymous kind soul 🤔 I cannot wait to try it out tonight.

Catheter has been changed. Unfortunately not a great experience but I'm still smiling and I'll be okay after maybe a shot of whiskey.

David is home early and will be off for the next two days. I get to spend the day with Merla tomorrow while David does a man date with his friend. I cannot wait!

Now to pick up the recliner but probably not today. But very soon.

David definitely has me be on Christmas this year! Not quite sure how I'm going to match this one.

#rockinALS +4 fotografie

23. (19. listopad 2022) What is the best thing about your journey with ALS?

The best thing about my journey, this is kind of a strange question. Some would say that ALS is not a preferred journey. I say maybe I have it so I can help others become more aware. There is always a purpose for everything. Right?

Yeah I kinda got the pooppy end of the stick. Honestly though ALS has given me a new reason to fight. There are days I want to completely give up and that is ok. (Usually no one sees those days unless you are my husband.)

Other days I am all about a challenge. (This is a BIG challenge)

The best thing about this Journey is the love and support I get from all of you. However my husband David gets the BIGGEST kudos. Without him I am not sure how this journey would be. He is definitely my rock.

The best moment of my ALS journey , Feb 28, 2020 (I can change the question if I want to) would be snorkeling with my husband and Aunt Holly at Discovery Cove. Actually I was not swimming. I was floating, and I am sure if my face was not wet you would see the tears of joy. It was the best experience I have ever had in my entire life. I felt normal and would have stayed there forever 🤔

#alsawarenesschallenge #rockinALS +fotografie

24. (13. listopad 2021) How did ALS clinic go?

Well to be honest I had typed it huge post before this and I took too long to type it that Facebook refreshed. ☹️

So here is the quick version. We are decreasing the baclofen as I am a limp noodle. The team is in favor of the tracheostomy as I dropped from 56% to 37% lung function in two months. My right hand is squeezing 5 pounds now and the left we did not test as it is at 0.

My chair control will be done by my people from the back of my chair and eventually I will have a program to operate everything with my eyes.

So much preparation in so little time.

#rockinals +fotografie

25. (5. listopad 2021) Tracheostomy supplies are now on order. I just got my phone call from respiratory. They are planning to gather all materials and supplies before surgery. It's getting real! Elizabeth has 25 years of invasive ventilation and Kate is the bomb diggity! They are also going to get refresher training which makes me even happier.

Friendly reminders were

I cannot be alone. Reliable care with an open mind is necessary.

After surgery I will no longer be able to talk but great news is I have an amazing way to communicate and you'll still hear my voice.

My care will need to be done by the book no shortcuts.

Got to find a generator that will run the house with all the vital machines that I have to use.

Thank you Coastal med tech, Brenda and Doctor Noack ☹️

#rockinALS #tamuraisadventure +3 fotografie

26. (22. říjen 2021) All my life minus my goat rash 3 years ago. I have had perfect skin on my face. I never washed my face with soap, just warm water and a little hair conditioner to remove my eye makeup. Never oily and never dry. I know some would think you should use soap but if I did I would break out in all pimples so water was the best medicine for my skin.

Malnutrition and dehydration is dangerous for sure, (not being fully honest on what I could or couldn't do) and it was not good to my skin or hair.

My feeding pump is my best friend and always hooked up to me! 🤔

This is so frustrating, if you see me close you can visually see all of the crusties. All over my face. My face feels like a mud mask is still on it and it's cracking. I could care less about wrinkles, I love wrinkles, I believe wrinkles are a sign of wisdom and happiness. I don't need a filter to hide everything. I do however need to find something that is not going to make it worse. Why it is so important when you have ALS to tell others the difficulties that you are having. Even if it is the hardest thing. Eating and drinking are so hard for me to do, I just took too long to tell somebody.

#rockinALS #tamuraisadventure +5 *fotografii*

27. (10. říjen 2021) Last night I hit a hard turn around 7pm. My body, my speech, chewing and swallowing. We woke up at 9 this morning and watched church with our four legged friends.

I feel weak, everything that touches my skin causes pain. However this guy has figured out a way to make sure we are warm and he doesn't hurt. 🤔

Meet my grandson Leo 🤔

Planning on a local adventure with David. Movies and dinner.

#tamuraisadventure #rockinALS +5 *fotografii*


28. (8. říjen 2021) Little did I know that this accomplishment will be one of many. Little did I know that in 12 Days from this accomplishment I would get knocked down so hard.

Look at me now! You can knock me down but I WILL continue to push forward.

In 12 Days I will be celebrating my 2nd ALS Birthday with God and my family by my side.

My adventures will never stop.

#tamuraisadventure #rockinALS +*fotografie*

29. (1. říjen 2021) do you consider ALS a blessing or a curse to know the general idea of when your time on this world is coming to an end? 
I consider it neither. when I'm given a time limit I set a goal to exceed, That time limit was 6 months to a year. I have surpassed both. On October 18th, 2021, I have lived with ALS two years!
I take life as a challenge and a purpose. So when my purpose is done off to heaven I go.
#rockinALS #tamuraisadventure +fotografie

30a. (10. září 2021) What does ALS feel like?

Let me see if I can put it into words...

Hands, have you ever carried a heavy item and when you put it down your fingers won't move, they are stiff. After a moment they return to normal. Well for me they don't, they remain stiff and very weak, I can't grasp or lift a pen with my left hand and a 1 pound weight in the right hand feels like 50 pounds.

Legs, when they aren't cramping they are weak and unresponsive. They don't respond to my desired requests. I stare at them trying to make movement and nothing happens except exhaustion. They actually feel as though I have 500 pound ankle weights strapped to each leg. My knees and ankles ache from the lack of muscles holding them together.

Eating, first off it is unavoidable that ALS takes the ability to swallow, however it begins with the tongue. You see the tongue becomes unresponsive and difficult to control. At this point imagine getting anesthesia in your mouth and your tongue is affected. In essence manipulation of food is challenging. This makes it difficult to move food away from the back of your throat causing frequent gagging. Now the epiglottis, the flap that separates your airway from your esophagus, well it starts to falter, allowing food to remain at the opening. This causes repeated swallowing and can lead to coughing and choking. Typically, pickles, dry goods, peanut butter, grapes, and cheese with cause this reaction.

30b. Laryngeal spasms, has your dog ever sounded like they are about to hack up a furr ball? That's a spasm, in a person it sounds very scary. Imagine getting the wind knocked out of you, when you try and take a breath you can't... that's what it sounds like.

Neck, many ALS patients lose muscle strength and tone in the neck as it progresses, thus needing neck braces or head restraints. Imagine having a 50 pound weight on your head, eventually you can't hold your head up. Many patients appear to be looking down constantly. Some become locked in this position.

Breathing, try this at home.

Gather the following: large shake straw, regular straw and a coffee stirrer. Now try this, take a normal healthy breath, now repeat breathing through each straw. You have just simulated progressive respiratory decline in an ALS patient. Now don't panic and catch your breath.

30c. Last exercise, now find a busy location in your home, sit in a chair and don't move or speak. Think of your favorite drink or snack. Now without speaking or moving communicate to your family that you would like that drink or snack. You want to get the real experience, try using a patient's eyegaze computer, let's time how long it takes to get frustrated? Imagine having to poop or pee. A typical person gets the feeling and goes. A person with ALS has to depend on others to get them strapped up in the sling for the hooyer and lift them out of the chair and on the toilet, fast enough, as there is no control of muscles in the rectum or the bladder anymore. The urge comes and it turns into a game show of the human claw machine over the toilet hoping there is no mess.

This is what ALS feels like to me.

#rockinALS #tamuraisadventure #alssisohard +fotografie

31. (4. září 2021) Did you know that when ALS progression increases the loss of energy it also decrease the ability to eat and drink properly. Malnourishment and dehydration can cause baldness. Before I got my feeding pump I could only eat 400-600 calories and drink about 30 ounces of water a day. Why not use your feeding tube? We did, however when you have ALS and a gastric sleeve you are at a higher risk. Using a syringe to provide fluids and nutrition was nearly impossible. I could only handle 120ml at a time. That is a half of a cup. Giving more caused reflux due to only having 20% of a normal stomach. Now we are in a good position! Night two was great. My urine is flowing great and clear. 6 months of getting all the nutrition in 3 cups of Kate farms will hopefully clear up my skin and fill in my bald spots.
#rockinALS +fotografie a video

32. (19. srpna 2021) Choking has been an issue So crushing up the meds and putting them through my peg tube is the next the step. The weirdest part is tasting everything backwards. Because I have a small stomach it fills up quickly so instead of having the meds dissolved in my mouth the dissolved meds hit the bottom of my throat.
#rockinALS +fotografie a video

33. (5. srpna 2021) Yesterday and today I feel like I did just before my week in the hospital. I'm pretty sure I have a double ear infection. My mobility in my left arm is only 5%. Pushing buttons on my chair and even a TV remote. Just a week of being ill caused my progression to speed up. Due to the increased weakness bowel movements are not easy as I do not have the muscles to help. 8 days with miralax and benefiber. Bloating tight. Straightening my fingers is impossible, I choke on saliva, my water intake is horrible so I will need to use my tube for water. My calorie intake is 600-900 a day, so formula feeding is starting today. It's okay I got this and I made an appointment for my ears. Not whining just being honest and real. Getting sick just a little makes everything so much worse.
#rockinALS + 2 fotografie a video

34. (7. června 2021) Everything has been finalized on the new gadgets I will be adding to my chair. Unfortunately after I add the arm troughs it does add about 4 in additional to the sides and I lose the mounting features under the arms. So the only mounting part that we will have will be on the base of my chair which adds an additional two to four inches. Making it a little difficult to get through normal sized doors. The headrest will support my head so much better as I am experiencing head drop or that's at least what I call it very similar to foot drop. No more neck pain Hopefully and a more comfortable seating option with an amazing cool headband lol. Today we also got the Alexa ring and door opening device! This is super exciting because now is somebody rings the doorbell I can actually open the door for the person if I am alone. 🗉 Also I can go swimming! As long as we can get in with my hoyer and a beach chair. I just have to add a cute little attachment to my catheter. #rockinALS #accessibilitymatters + 4 fotografie

35. (25. května 2021) Day 25- ALS Awareness Month. Did you know that when an ALS patient loses their muscles due to the nerves dying that literally we are only skin and bones. Never in my life have I had loose skin/ jiggly skin. We can't just go get it removed or have it tightened up. I wish I could share a photo with you of what my body looks like.(I do have one that I took this morning) I saw myself in a full size mirror today and I am something that resembles a melting snowman. I mean it is warm here in Virginia but the body that I had worked so hard for is no longer the body I have now. I have no muscle and when you lift one of my limbs or even my body the skin just hangs down over the bone and you can see what my bones look like. This isn't to make you sad or upset nor is it a negative post. I just wanted to share and observation I saw this morning. I'm an average girl 5'9 and 175 lbs and I'm melting. #ALSAwarenessMonth #rockinALS #Everymomentmatters +fotografie

36a. (21. března 2021) How did ALS progress and how rapidly did it happen?

My ALS started before I even realized it. Someone from work actually noticed something was wrong. I started walking with a gait, this was noticed in the summer of 2018. In 2019 other things started to get worse, I would start to trip myself. The falls would start 1 or 2 times a week to up to 10-15 times a week. The falls started to get so bad I lost track and I would try to hide the bruises on my legs and arms.

In January of 2019 I could not get my left foot to work when putting on shoes. By the summer of 2019 I had fallen in 1 year over 100 times, I started to favor my left leg more. By September of 2019 I lost full mobility of my left leg but could walk with a walker. When I had my diagnosis from Dr. Rock, I was then referred to ALS specialist and the best in Maine, there it was confirmed ALS.

In November of 2019, Dr. Taylor said walking is no longer safe and that I would need a wheelchair. I was still driving at that time as my right leg was still fully strong. By December of 2019 I stopped driving as I was lifting my right leg to push on the pedals.

36b. Jan 2020, I was fully using a motorized chair, unable to lift my arms above my head and lost more strength.

Feb 2020, No longer can walk even with guidance, but can stand. Can not swim without help. Showering with assistance and bathing.

April 2020, I now strain to talk and am on a ventilator for breathing at night and sometimes during the day if needed for exhaustion.

May 2020, I wear braces to help support my right ankle as now it rolls when I try to stand.

August 2020, I received my Trilogy Eye Gaze and will be practicing more for communication.

September 2020, I had surgery for the PEG tube (feeding tube) and Suprapubic Catheter. Lots of surgery complications.

In October 2020, I was diagnosed with a severe DVT (blood clot) in my left leg and am no longer able to physically stand.

In January 2021, My breathing and strength has significantly decreased.

#alsawareness #rockinALS +2 fotografie

Pacient 2

20

Pacient

1. (26. květen 2021) My friend said she was about to do her least favorite thing- dusting. I told her to wear a mask. She asked, For dusting? My response was, I am not the one with a breathing problem. Oh, wait. I'm on a ventilator. How quickly, sometimes, we get acclimated to a situation and accept it as normal. Some people have an experience that is their normal that they have accepted as everyone's normal. Physical, emotional, and all the other abuses, are not normal. Please get help in breaking the cycle. There is an entirely different life awaiting you. Sometimes we settle for the familiar because we're afraid of the unknown. Embrace your ALS- Adjusting Life Style.

2. (24. květen 2021) The best part of waking up is the realization that I am blessed to be God's child. I contribute to the enjoyment of the day just by my attitude. Opening grateful eyes is a thrill from where my head rests each night. I am still working on seeing all the good possible in others. We are all blessed with some awesome opportunities. I once was blind, but now I see. Grace be with you, mercy, and peace, from God the Father, and from the Lord Jesus Christ. 2 John 3. KJV. ALS- A Loser Saved. Thanks, Zet.

3. (15. květen 2021) The experience of flying can be both exhilarating and frightening. Some people are visibly shaken when flying in a commercial jet. The take off and landing are foreboding to some people, while the rough air turbulence scares quite a few of us. However, the more we travel by air, the more we become comfortable with and understand and expect certain outcomes. We have traveled enough through this life to understand that certain parts of our journey will be bumpy. If it's raining when you look out of the window, climb higher than the clouds. The sun is ALS- Always Left Shining.

4. (6. květen 2021) Today I woke up refreshed and hungry. My appetite for food and life is undiminished. Once, getting up early and planting flowers was part of my enjoyment. However, it is a tremendous blessing to see all the beautiful flowers that I have a part in planting and God grows. I no longer own that home and involvement in flowers painting the yard is definitely close to nonexistent. Now, amazingly, I have been blessed to plant words into the minds of many and I enjoy beholding what the Gardener of all of our lives grows. Painting lives with broad strokes of love and encouragement are superior to the botanical experience. I'm grateful for the opportunity of ALS- Always Loving Someone.

5. (24. duben 2021) I'm no longer able to take my car in for a tuneup. Who doesn't appreciate a smooth running vehicle? Unfortunately, we sometimes get accustomed to chugging along because the change is imperceptible until the the loss off power is unmistakable. Similarly, our thinking can get into rough running as opposed to the purring of peace that passes reasonable understanding. I'm getting a mental tuneup this month. I have a lot of road and life to cover. ALS- A Long Stroll. Thanks, Bena.

6. (21. duben 2021) It's been a couple of years since I exclaimed, Hold my mule while I shout. I am in love with the Creator above what He's created. I would like to continue to praise our God for His Word being sure. Though the financial entity played a part in our new mule back then, a new Toyota Sienna, I am banking on Jesus. He is where I have confidence, and from Whom all blessings flow. I'm careful to praise God with a grateful voice and heart for moving to a facility closer to my family and with a private room recently. Then shalt thou delight thyself in the Lord; and I will cause thee to ride upon the high places of the earth, and feed thee with the heritage of Jacob thy father: for the mouth of the Lord hath spoken it. Isaiah 58:14 KJV. I am the Lord: that is my name: and my glory will I not give to another, neither my praise to graven images. Isaiah 42:8 KJV. ALS- A Lifelong Song. Thanks, Joann. *+fotografie*

7. (12. duben 2021) The joy of stability. I'm very thankful for the reliability, good or bad, of some people. I know their history and can prepare mentally for the norm. My weight and health have also been consistent. I can exercise and meal plan effectively based on this knowledge. I wake up happy almost everyday. My appreciation of grace and my life experiences continue. I hope for you a great temperament for every test and a testimony of thankfulness. ALS- Another Life Solution.

8. (8. duben 2021) I'm loving how many of my age are now cruising into retirement. How awesome to work and reach some level of accomplishment that now it is rest time. Not just the kick up your heels rest, but what will you do with the REST of your life. You have definitely earned the right to chill. However, there is a world gone mad that could use our perspective, discernment, compassion, and godly love. Enter to learn; depart to serve is now available. When we had a job, we were limited. Before our lights grow dim, let's light it up for Jesus with no limitations. ALS- A Living Servant. To them God has chosen to make known among the Gentiles the glorious riches of this mystery, which is Christ in you, the hope of glory. Colosians 1:27 NIV.

9. (6. duben 2021) I am grateful for many things, but one day I was wonderfully surprised by one of my former care givers dropping by with gifts. She and her son had picked out jerseys of the Anaheim baseball and hockey teams for me. You sometimes read stories of my experience. Praise God for those who are a positive impact in their caregiver responsibilities and services. I am so grateful for the good ones. And, thanks be to God for the bad caregivers that increase our prayer lives. Pray without ceasing. 18 In everything give thanks: for this is the will of God in Christ Jesus concerning you. 1 Thessalonians 5:17-18 KJV. ALS- Appreciating Lovely Surprises. Thanks, Tonya.

10. (2. duben 2021) I finished listening to a book about gratitude, Gratitude: A Way Of Life by, Louise L Hay. Now I know better why I am so happy. It turns out that being grateful is huge in just about every aspect of life. I've mentioned how re-framing is monumental in getting past the earlier experiences in life that were harmful, hurtful, and devastating. Being grateful is like a superpower that doesn't cover up or ignore the unpleasant incidents in life but rather embraces them and finds what is a positive and beneficial reason to be thankful because of them. I admit that it can be a stretch, but that is a characteristic of the Fantastic Four. Not the Marvel comic book team. I'm talking about the Father, Son, Holy Spirit, and you with ALS- Attitude Leveraging Superpowers.

11. (23. března 2021) Don't let your pain, struggle, or trial be wasted. Someone may benefit from your empathy because you have traveled similar roads. Every journey is different, but our challenges often band us together.

I remember being asked by a friend what were some of my signals that I had ALS? I hated that he joined me in the fight against giving into this monster, but I was glad I could help encourage and support him until he finished his last round. I just love how God has pulled it altogether in my life that none of my pain has been wasted.

I also one day recognized the pain and frustration in the voice of a coworker when I said, "Good day mate." Her response of, "There's nothing good about it" caused me to zero in and reflect that I had a day like that going through a divorce. She said, "Bingo!" I tell you, it took every thing in me to hold back my tears for her until another time when I invited her to lunch so she could vent.

It's a good thing to not waste our experience when it can make us better and someday bless someone who could use some understanding support. Whenever possible, be ALS- Another Life Support. Making my hurt some good is so good.

12. (19. března 2021) Life is good. I didn't receive any items left at the old place, so I will have my wife buy more. She does my laundry now so I am no longer hunting for things.

It's a tremendous task getting everyone here at the new facility familiar with me at one time, especially when they have not had a ventilator resident in about two years. We are making great progress.

Helping the kitchen with time, temperature, texture, and taste will be ongoing for a while. I'm excited that they have ordered my eggplant online and purchased an air fryer. It is awesome having my wife's food, cakes, and pies. Fettuccine, broccoli, and peach cobbler will be today.

I leave my blinds open and the morning sunlight comes in. I see my wife or daughter four times a week. The view has significantly improved with their smiling faces.

Currently, I am not allowed to go to the bathroom without a therapist present to transfer me. Bummer, but it will take a while for them to feel comfortable with what I can do safely during the transfer from the bed to the commode chair and rolled to the bathroom for ALS. Fill in the blanks.

13. (16. březen 2021) Thanks for your prayers and well wishes. I definitely have a more responsive director and assistant. People are trying to learn how to care for me.

I like the plans with the therapists and how I finally am getting a more consistent movement of my arms every two hours and range of motion twice a day soon.

The cooks will improve as I give them feedback for how to prepare my food. Of course, it's great having my wife bringing me food also, including some of her pies and cakes.

Having a private room is definitely also wonderful. My daughter's visits are special along with my wife's. So, I see one of them on Sunday, Tuesday, Thursday, and Saturday.

I'm on book reading for the year number 53. Life is still good in Jesus. +2
fotografie

14. (8. březen 2021) I'm doing my normal well with the exception that I was med flight transferred from Fresno to Garden Grove, CA on last Tuesday. From the time I left the facility, I was in the air within 45 minutes.

I am definitely loving my private room. So far I love the DON and RT. I'm working with the PT to get evaluated so I can be allowed to be more mobile. Today I did get on a table that rotated to different upright degrees to walk in place safely.

They have not had a ventilator resident for a couple of years, so most of the nurses are learning that as well as becoming acquainted with me.

The cook is preparing my food nicely but too much of it. So far I am pleased with the timing and taste. They bring little packets of salt and pepper so that helps tremendously.

I have immediately asked for attention to the hydro bath, but when I got in it today it didn't meet my needs.

The Activities Coordinator washed and vacuumed my wheelchair the same day I arrived.

I'm enjoying my wife's cooking already. Yesterday I was brought a lemon pound cake. Kayla's visit Saturday was also sweet. +*fotografie*

15. (4. září 2020) The loss of breath and the desperate desire to have more of them is a glimpse of the craving for life and living some feel as ALS slowly takes away the ease of breathing and living life. It's unreal how dialed in is the precious awareness of what is important- the certainty and clarity are unbelievable. It becomes a time to maximize some relationships and to cut loose others. I know I checked on my insurance and was totally confident in my Blessed Assurance. Knowing how much is in the bank is great, but for me, knowing my name is written "there" has given me peace in the midst of the storm. ALS- Am Loving Solace. Thanks, Sandy.
+fotografie

16. (1. září 2020) Don't be a co-star in your own life. Take center stage with a commanding presence. I'm bedridden and unable to move, and yet, I am still a mover and shaker. It has been said that I intimidate people. That is funny to me. My stance is to self-advocate for my health care excellence. I am relentless and thorough in my observations. Tempering my frankness, I still get the message across. Nothing makes me happier than saying, "Good job." People respond better when they are appreciated. We are all learning together. Help me help you. I loved it in the movie, and I am excited to make things happen in my life. I'm my own CEO- Chief Encouraging Officer with an ALS- Awesome Life Shared. Thanks, Stella.

17. (30. srpen 2020) August has been another awesome month. I enjoyed participating in the ALS Fundraiser for a cure and treatment. I also joined another awesome support group on Facebook. I'm feeling good about how many people actually take time to care about others, and the surrounding support of shared experiences is phenomenally exhilarating. We are not alone. When you take the time to reach out, you make a difference. This world becomes a better place. Thank you for being an ALS-Amazing Light Source. Thanks, Julie.

18. (28. srpen 2020) Okay, let's get this party started. Today is the day, eleven years ago, that I received my diagnosis of ALS. Well, to be clear, I am celebrating life. Even with many dimensions diminished, I am living a full life. If the essence of existence is loving and being loved, I am totally there. If the meaning of life is caring and sharing, every day brings me the opportunity to fulfill this purpose. So, as a prisoner bound by the chains of immobility, I daily take my walk of faith. I don't take it for granted that the ventilator pushed air helps my lungs to expand. Whatever muscles still responding to my mental commands are occasions for an emotionally happy dance. Don't get it twisted- this is hard stuff with a physical disability. However, I have been battle-worn and I refuse to concede to the loss of any mental or spiritual ground I have gained. Today, party with me, and if you haven't already, get your party started with ALS- Amazingly Lighthearted Spirits.

19. (27. srpen 2020) There, I said it, ALS. Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's Disease. I'll always have a hard time spelling it, but when spelled out, it is a neurodegenerative disease that affects the nerve and muscle slowly for some, and more rapidly for others, to the point, most voluntary functions are eventually lost. A captive to a dysfunctional body, some give up or out and die within a few years of diagnosis. What you think and what you believe comes quickly to the forefront! Eleven years ago, I heard the sad and serious tone of my Neurosurgeon doctor who assisted in my journey of getting a correct diagnosis. I laughed and said, "At least I don't have to have surgery." I could laugh at death because to me ALS meant A Loving Savior! I'm in His care and He has the last word concerning my life temporal and eternal.

20. (27. srpen 2020) Hello everyone. I'm Chris in Central California. I was diagnosed eleven years ago this month. I live in a sub-acute facility and for the most part, it's a good life. I post daily, have a website, and have compiled four devotionals. My family is 280 miles away waiting for my transfer to take place to a facility 30 miles from our new home. My wife is retired and my daughter just graduated from the nursing program at Loma Linda University. She takes the state boards next month. Recently, I completed 800 hours as a Crisis Text Line Counselor. I'm awaiting a virtual position with the Veterans Crises Line. My faith is strong, my health momentarily plateaued, and to my knowledge, my mental health is good. I have been on a ventilator for 3 years. I have a G tube but I eat solids for two meals a day. I believe in ALS- Always Lifting Someone. *+fotografie*

Pacient 3

22

Pacient

1. (11. března 2022) One of my friends got me the best shirt ever!
+fotografie (zobrazující fotku osoby s vtipným nápisem)

2. (26. únor 2022) The VA rules! Just got my custom AFO's and they actually made them camo to match my power wheelchair! Standing is easy again! *+fotografie*

3. (17. únor 2022)



4. (16. únor 2022) Practiced with the Tobii machine today!! It's crazy the technology that has been created to help us! Despite the horrible disease, I am thankful to benefit from all the technology created to keep me functioning with it! +3 fotografie

5. (9. únor 2022) Found a guy on Etsy who 3D prints joystick toppers, got a few made of my favorite hero/character: Judge Dredd! The wife did the great paint job!


6. (21. leden 2022) Got a new toilevator so my wife doesn't blow out her back trying to lift my big butt off the toilet anymore! + 2 *fotografie*

7. (7. prosinec 2021) Ain't no ALS slowing my roll! 70 mph down desert trails in a UTV today! Fuck ALS!!! +video a 10 fotografií

8. (14. říjen 2021) Okay, so I have the problem with easily triggered laughing, psuedo bulbar affect. Makes reprimanding or having serious talks with our two young kids almost impossible. So the doc gave me Neudexta.

Then I read the label. It cautions you against taking it with marijuana, which I do medically. Marijuana is actually quite helpful in helping me sleep and when I take it during the day it definitely helps control my tremors and helps make my motions smoother and more coordinated. Has anyone here been on Neudexta and marijuana at the same time? What were the reactions if any? And for anyone who just takes Neudexta, how well does it work for you? Is it worth it?

9. (10. říjen 2021) From the cold south rim of the Grand Canyon to water tubing and water skiing in the same week! Gotta love Arizona's different climates!

Thanks to Arizona Adaptive Water Sports (AAWS) my family got to have an awesome day on the water! I got to do the water tubing and water skiing, and the kids and wife got to go kayaking, swimming and using a water slide off a double decker party boat. My son's favorite dive is called "The Starfish"  +15 *fotografí*

10. (6. říjen 2021) Got to do a day trip to the Grand Canyon and Sedona yesterday with the family! And what a gorgeous day for it! +10 *fotografí*

11. (1. říjen 2021) So just a question:

I spent the past two months dealing with kidney stones, dual stents and 2 surgeries. This has led to me being in a huge amount of pain, and to deal with it, I slept in my power wheelchair for the majority of the time.

Now in that time my wife bought Sleep Number mattresses for us, we each have a twin xl with the motorized bases where the head and feet can raise and lower. The new mattress is about 2 inches lower than the old one, apparently that is too low for me to be able to get up off it to transfer to my wheelchair.

So then we put the extended legs on the base, lifting the bed approximately 6 inches up. Now it is life-threatening to try to get into. My wife usually lifts my left leg up onto the bed then I roll up into bed. Now with it higher, I feel like I am doing a split and my leg feels like it's going to pop out of the socket.

How do other people here get their loved ones onto the bed in a situation like this? I would like to continue to try to transfer myself as long as possible, and I hate being scared of my own bed. 😊

12. (6. září 2021) Hell everyone! So I have a question:

I live in Arizona, and as some of you may know, it gets a little warm out. I use a Quantum Edge 3 power wheelchair to get around. Whenever I find myself outside (like at a block party we were having today) even if I am in the shade, my joystick controller gets NUCLEAR HOT!!! Almost to the point it's too hot to touch, that can't be good for the electronics.

Does anyone know of a cover or something to prevent this?

13. (24. srpen 2021) Public service announcement:

Drink lots and lots of water! Stay away from sodas and energy drinks all the time like I did.

Apparently being wheelchair bound makes you more susceptible to kidney stones, as you are not bouncing around on your feet all the time like you used to.

Had to go to the ER on Sunday night for continued kidney stone pain that I got diagnosed with two weeks ago and it still hadn't passed. They did a CT Scan and found out it wasn't 4mm like the other ER had estimated 2 weeks ago, but instead 6mm x 3mm, and was currently stuck between the bladder and kidney and wasn't going anywhere. So I got to do an emergency surgery to put in a stent. 😞

Now they are going to have to go in again and break it up with a laser and remove the stone, then remove the stent at another date after that. I should have just drank more water 😞

And of course the doctors wouldn't let me take my riluzol or baclofen while I was recovering so I was stiff as a board and shaking like a leaf the whole time at the hospital.

All in all, ALS + Kidney stones = hell on earth!

14. (12. srpen 2021) Last month (the whole month) I had and beat pneumonia.

Today I just got my first ever kidney stone.

This is just not my summer!

15. (5. srpna 2021) I try hard every day to find something I have done to be proud of...

Today I vacuumed a couple rooms in our house while motoring around in my power wheelchair. It was then when I realized that for those few fleeting moments, that I had become the world's most expensive Roomba.

16. (28. červenec 2021) So, food for thought: And I am by no means a medical professional or offering medical advice! But I have a theory that backs up a thing I heard from my physical therapist today.

Today my PT came and we have been discussing supplements and stuff that may help me with slowing progression and possibly maintaining muscle. The supplements B12, L-Carnatine, Taurine, creatine, etc came up in his recommendations to me...

Then I remembered, I had been addicted to energy drinks from 2005-2018. I averaged about 2-4 drinks a day. Monster, Red Bull, Rockstar, NOS, etc. funny thing: I decided around late August 2018 to break my addiction once and for all...then my foot drop and limping began in October 2018...

Now pretty much all the supplements my PT mentioned are main ingredients in energy drinks! Is it possible that my daily consumption of those energy drinks was delaying the onset of my symptoms by providing me with a daily dose of those supplements? And now I will be continuing my addiction anyway because I need to get those supplements now anyway, and screw it, why not drink the stuff anyway, not like I am too worried about the long term health effects (just saying ♂).

Just food for thought, wonder what anyone else thinks. (PS: I am 36 years old, onset was 34)

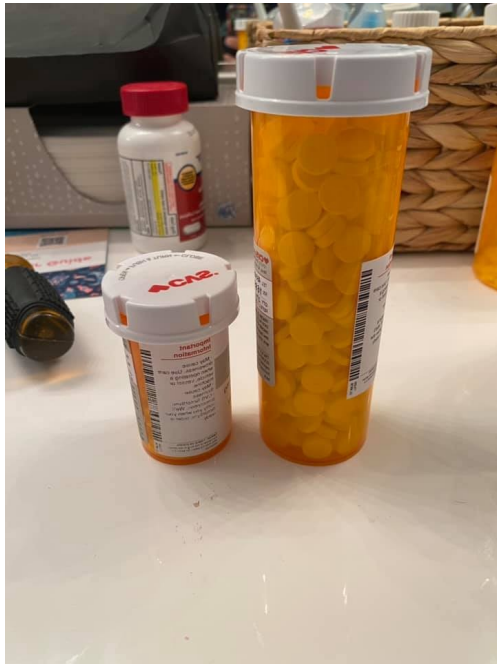
17. (13. červen 2021) Just got my first bottle of ReQuip CR from my doctor to start taking tomorrow. Anyone here have any experience with this med? Hoping it helps slow progression as some research has suggested. [?](#)

18. (31. květen 2021) Took the family out to Monster Jam today. ALS sucks, but I will tell you what doesn't: front row parking and a private balcony for wheelchair access for the family! I will never let ALS stop me from having fun!!! +14 *fotografií*

19. (13. duben 2021) When getting a power wheelchair, always opt for the PosiTraction option.... 😊
This is why I can't be trusted with nice things. +3 *fotografie*

20. (17. březen 2021) Just got these sheets, hopefully no more wrestling with a bundle of crappy sheets wrapped around my legs halfway through the night! +3 *fotografie*

21. (5. březen 2021) Well CVS, I don't think I will be running out of Baclofen anytime soon.... 📷 +fotografie



22. (12. únor 2021) Absolute game changer when the dexterity in your dominant hand is diminished!! I have never used a bidet before, and was very nervous spending this much money, but it was ABSOLUTELY worth it!!! +fotografie

Pacient 4

12

Pacient

1. (1. březen 2022) Happy pancake day everyone!

Today I am launching my next challenge, I am going to transform myself into an Easter MND bunny. My aim is to spread awareness of this disease and at the same time delivering Easter gifts to children in my local area. Weather permitting I will be out on my scooter delivering gifts. If you would like to donate Easter eggs or Easter gifts that would be great. Children have had a tough few years and with everything that is going on at the moment it will be lovely to bring a smile to so many faces.

Watch this space to see me dressed as the MND Easter bunny
📷 just waiting for my costume to come through. +2 fotografie

2. (27. únor 2022) I just wanted to say Thankyou to everyone who sends me such lovely messages. I am often told I am inspirational but your messages really inspire me Thankyou 📷

📷📷📷📷 +video

3a. (25. únor 2022) I think we are all thinking the same watching the horrific events happening in Ukraine. I really didn't think I would see this again in my lifetime. So I wanted to share with you a message I had today, I have had permission from the sender as long as I deleted the names. What this shows is that we can't control everything that is going on, but a little bit of kindness can make a difference to others.

Hi John

I just wanted to send you a personal message to let you know what you have done for me.

My beautiful husband passed away 14 months ago from the beast MND. I have not got over the fact that our future together has been taken away.

His final wish was for me to scatter his ashes in one of our favourite places. I have not had the strength to do this as I felt I was letting him go.

3b. I have been following your story and some days you make me laugh some days you make me cry. The one thing you have done for me John is give me strength, after all if you can keep smiling so can I.

Yesterday I put your photo on my screensaver on my phone and drove to our special place. I let him go and all the time I looked at your photo and told him all about you.

I feel so much better now I have carried out his final wish.

Today I have found the strength to sort through his things to donate to other sufferers.

Never under estimate how much you help others John , I am now on a mission to stand by your side and raise funds to find a cure.

Keep smiling, keep fighting and Thankyou from the bottom of my heart for helping me to take a more positive direction.

You are a true warrior and loved by so many.

Forever grateful

4. (24. únor 2022) After a successful few days of exercise 🤔 I thought I would try out my new tankini and go for a run. (Not really me in the picture but I thought it was funny) +2 *fotografie*

5. (22. únor 2022) Yesterday I set myself a challenge to walk 10 steps with my walking frame ! and I did it 🤗very proud of myself 😊set yourself a little challenge today it certainly makes you feel more positive 🤗🤗🤗
#PositiveVibes
#everydayisablessing +2 *fotografie*

6. (20. únor 2022) Drum roll 🥁😊😊

We have just counted the valentines cards and I have received an amazing total of 441!!

Thankyou so much everyone ♥ I have loved reading every single one ♥ I don't know what I will do with myself tomorrow I look forward to the postman coming 📧 maybe my next challenge should be how many birthday cards I receive 📧😊😊

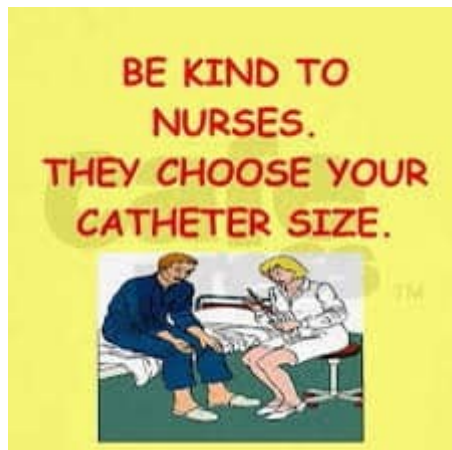
We have raised $441 \times £5 = £2205$

For MND research and all the stamps have gone to Stamp Out Mnd

♥♥♥♥♥♥♥♥♥♥♥♥♥♥♥♥ +4 fotografie

7. (19. únor 2022) What a windy day yesterday! My wig blew off 📧 and look what I have now 😊😊 +2 fotografie

8. (18. únor 2022) To all my warrior friends who have catheters remember this 🤔🤔



9. (17. únor 2022) I have been very busy today ordering a few things for my summer collection

🤔🤔🤔🤔🤔

🤔🤔🤔🤔🤔🤔 +3 fotografie

10. (16. únor 2022) I started in November on a campaign to raise awareness and to raise funds for research into this horrendous disease. I have set numerous challenges and I have raised an amazing £11,500 ☺ my recent goal was to receive as many valentines as I could , as I was being sponsored £5 per card! I have received over 300 cards ! Together we have to fight on ☺☺
Sending valentines love to you all ♥♥♥♥♥♥♥♥
<https://www.justgiving.com/fundraising/John-adams44> +3
fotografie

11. (16. únor 2022) Sorry everyone ☺ the Alliens are coming ☺☺☺ +2 *fotografie*



12. (15. únor 2022) Good morning all my warrior friends 😊 it is a horrible day here in the uk r☔ I am looking forward to seeing a bit of sunshine ✨
📺📺📺📺📺📺📺 +video

Pečovatel 1

10

Pečovatel (manželka)

1. (28. srpna 2021) My Johnny gained his wings 8 days ago. I feel as though I'm simply going through the motions in everything that I do. Like none of it is actually taking place. This disease took away the love of my life. The loss is incredible....

2. (19. srpna 2021) Had a tough day today. Everyday is tough, to some extent, but today was more so. I wore myself out, mowing the lawn, cleaning the house, that when it came time for unexpected ALS craziness, I was exhausted. I'm finally sitting down and relaxing since being on my feet since 10a. Felt bad for my PALS, as I had a bit of crying spell. Feeling sorry for myself. Trying to tend to him while he was laying down flat, which makes it hard for him to breathe. It was tough. Pals looks diff today. More pronounced cheek bones, which means more sunken in cheeks and temples. So sad.... My Pals told me "I did good". I don't get that too often, so I'm rewarding myself with a bag of starburst. Oh, who am I kidding...I eat them almost nightly.

3. (3. červenec 2021) My Pals has changed, or declined quite a bit in the last month. I feel as though once he got his feeding tube. Not saying that the tube has anything to do with the decline, it's just a time marker.

Extremely tired

Restless

Moans nonstop

Legs and feet are hurting him badly

Looks so much more weak

Barely wants to leave his bed for the recliner

Barely smiles anymore

It's just heartbreaking

4. (3. červenec 2021) Does anyone know of a group of Soldiers(or veterans) that were diagnosed while still on active duty(enlisted)?

5. (28. březen 2021) I do not have a cough assist
Pals is trying to cough up phlegm,
How can I help???

6. (28. únor 2021) Hey all!

Question?

My Pals has been coughing lately. He claims it's a "tickle" or feels like a small chunk of something that he's not able to get out.

It seems to be mostly when he eats or drinks.

He will cough, over and over, and at times look as if he is dry heaving. Or coughing and can't get his breath. I'm not sure if I'm describing it correctly.

Is this him starting with the swallowing, cough, goop?

Ty

7. (11. prosinec 2020) Question for y'all?

My Pals presented in his arms and legs first. His speech started changing around Feb of this year. He mentioned to me tonight that his bottom lip is numb. I assume this is a normal part of the disease? I guess for me, I'm curious/scared if this is him progressing in those crucial areas?

8. (29. únor 2020) On a lighter note, I ordered these 17 inch bendy straws that open to 20 inches for John to drink with. He can't lift a glass or sit up and raise his arms to guide the straw, and can't reach the little straws. They are called Mammoth. [?????](#)

9. (29. únor 2020) Haven't posted in a couple of days. It's been a tough couple..

We had been trying to get into the ALS clinic in Memphis. They couldn't get us in until May, and the Chattanooga clinic, not until August. As we all know, many ALS wouldn't make it to those dates.

BUT, we had an Angel manage to get us in, in a month. Our appt was this last Thursday. Amazing, caring, understanding, supportive, knowledgeable staff. The first time I think we felt, good after a visit.

John took a pretty nasty fall at the clinic. Hit his head so hard, you prob could hear it a block away. Needless to say, we were sent to the ER for a CT scan to rule out any brain bleeds, etc.

John is ok! Nothing wrong with his head!!!

Me, on the other hand, broke down as soon as we were alone, headed to the ER. Out of pure exhaustion, desperately wanting to be at home, relaxed, etc. I just didn't know if I had it in me, to cont on that evening. I began to question my strength(mental, emotional, physical, spiritual), my abilities to care for other human beings. sometimes, I believe we question our very own existence.

10. (24. únor 2020) I don't normally share anything too personal. But I am learning that in order to get our Nation to understand the crippling severity of ALS, I need to be a bit more open.

I know one thing I miss being a caregiver of a Pals, is a hug, a tight embrace from my husband. It can be reassuring, supportive, warm, etc These are things that we take for granted every day. But when you can no longer have these, it affects you greatly. We understand that we are loved, but sometimes we just need that embrace.

This morning, I crawled back into bed and placed his arms around me. It was so very special and so very much needed, for both of us.

Missing his arms, his strength!

Pečovatel 2

15

Pečovatel (přítel)

1. (10. březen 2022) When you go from long term disability to social security disability insurance. What's the difference is pay and service? My gf is looking into a health insurance as well.

2. (17. únor 2022) Has anyone that takes or taken trazodone also taken cbd and or thc? Any bad affects?

3. (15. únor 2022) Has anyone ever worked by using the eye gaze? My gf/pALS is a copywriter and would like to go back to it until she totally can't.

I was wondering if you can use it for work.

4. (7. únor 2022) A little gross but my pALS is unable to use her hands. She's been having trouble getting dry nose gold out and is using q tips. I was wondering if there's anything that we can use instead?

5. (2. únor 2022) Has any pALS gone full vegan? Mine is and she's losing way too much weight.
Good? Bad?
I think we are going back to meats like turkey and chicken.

6. (6. leden 2022) I'm in search of a nurse practitioner that can come to the home and administer an antibiotic for lyme.
Tampa, Florida area?
Any suggestions?

7. (17. prosinec 2021) I'm thinking of a way to get my pALS gf on my insurance. She's too young for Medicare and I don't think she'll be able to get medicaid.
I'm thinking the only way is marriage but I'm hesitant. Has anyone done this?

8. (3. prosinec 2021) Has anyone in this group been to body science in florida?
Pros cons?

9. (3. prosinec 2021) What's a good product to help pALS hold onto utensils better?

10. (11. listopad 2021) At what point did you have to talk to your pALS about getting outside assistance?
Thinking a nurse for an hour or two a day.

11. (17. říjen 2021) I'm a bf for my als gf. I feel like I'm becoming more of a caregiver now and it's difficult to transfer back and forth.
Has anyone experienced this?
Do you become less of a partner?

12. (22. září 2021) My pALS is having a stretching or turning feeling in her muscles while she sleeps.
The cramping has been better but how, if we can, do we control the stretching feeling?
Has anyone experienced this feeling?

13. (31. červenec 2021) Any tips on decreasing muscles cramps/stiffness at Night?

My gf is 43 with als. Still gets around but gets very stiff at nights and sleeping is difficult.

I massage her once a week but is there anything I can give her that would help the muscle stiffness/cramping at night?

Btw this group is great. The disease effin sux

14. (29. červenec 2021) Not trying to have a political reaction or argument.

Has your doctors recommended getting the covid vaccine?

Has any als patients gotten it ? And what was your experience?

Thanks

15. (25. červenec 2021) How have you dealt with a loved one that totally doesn't believe or want to believe they have this?
We are going the remedy, supplement route but maybe med trials would be better?

Pečovatel 3

15

Pečovatel (dcera)

1. (14. březen 2022) I am leaving this group so that I can properly grieve my loss. I'd love to stay and offer advice, however, I need to separate myself from the reminders of this awful disease. I pray for continued patience, love, and hold on strong to your faith. This group has been very helpful. Continue to pay it forward.

2. (10. březen 2022) About 7 or 8 years ago, when my mom was 79/80 years old, she used to randomly drop things that she was holding, for no reason. She would get so upset. We used to say "You're getting old mom. Those things happen." Well those things don't happen unless something is wrong. In 2018, she started losing a lot of weight without trying. In 2019, she started losing her voice and the use of her left hand. In 2020 she was diagnosed with ALS. On Feb 1, 2022, at the age of 86, she was set free. Her dropping things was only the beginning of this disease.

Pečovatel 4

14

Pečovatel (manželka)

1. (10. březen 2022) Did any of your Pals use this wedge or something similar? I wonder if it is comfy *+fotografie*

2. (23. únor 2022) Hey everyone, its 430am and I am on and off sleep with F30 mask problem with lower lip of my pals escaping the mask. Apparently it only comes as medium in size and we need a chin strap to correct this. Is this true? What are your experiences? any tips? My pals hubby is getting fed up with all the changes . please help. Thank you in advance.

3. (9. březen 2022) What I've learned about this awful disease is everyone's symptoms can be completely opposite of someone else's. I've been in this group for about 2 years while caring for my Mom. I see posts about thickening mucous; my mom had issues with watery saliva. I see posts where PALS are able to do their own suctioning but couldn't walk; my mom could barely raise her arms, barely use her hands, and couldn't extend her fingers, but was able to walk. I saw posts about people not being able to blink or close their eyes; blinking was one of the last things my mom was able to do before she passed away. There's so much more, but these things weigh heavy on my mind when I see these posts. I feel terrible that anyone has to go through this. PALS & CALS, I pray for your strength, patience, spiritual guidance, and Love. 🙏🙏🙏
CALS, stay strong.
PALS, keep your faith. It will get you through to the end.

4. (3. únor 2022) On February 1st, 2022, my 86 year old mother ascended from her body which was slowly being brutalized by ALS. My beautiful and strong mother fought against this disease until one day I said to her, "Mom, please stop fighting. We will be OK. You are suffering way too much." About a week later, she broke free of this awful, awful disease. My heart is broken because I watched my mother suffer and I witnessed her health decline over the past 2 years. From day to day, week to week, and month to month, basic functions that we take for granted were stripped from her such as speaking, smiling, holding things with her hands, extending her fingers, eating, walking, getting dressed, etc. During her last days she was only able to respond by blinking. The only thing that ALS didn't strip her of was her mind. My Mom was aware of everything that was happening to her until her last moments. Knowing that my Mom is no longer trapped in her body and suffering with discomfort, pain, and lack of her independence, helps to bring me peace. She is free. 🙏
Please pray for my family while we get through this difficult time. *+fotografie*

4. (29. leden 2022) Hello, we are having our initial consultation with a Consultant who will assess my husband Pals for Cannabis treatment for anxiety tomorrow, I am a bit lost. Can anybody give me a clue to what I can ask? He is experiencing anxiety attack almost every night, some mild and a few major ones that lasts for more than hour. I find that when I massage him he feels better after, did anybody start with cannabis oil? Is it as effective as peg introduced? What are your experiences please.? Thank you in advance-

5. (10. leden 2022) My mom is 86 with ALS. Everyone automatically assumes that because she can't help herself at all, that she doesn't know what's going on. Why is that? My mother's memory is better than mine right now.

5. (25. leden 2022) Help!!! CPAP mask is marking my hubby's cute nose. What do you guys use please???? Thank you in advance.
+fotografie

6. (31. prosinec 2021) My mother's health has declined over the past 2 weeks, even since Christmas day. She is now down to blinking to respond. She is barely able to nod or shake her head or use her board to spell words. This disease is the worst! If it were a physical thing, I'd smash it to pieces.

6. (23. leden 2022) When I have a back pain, or a bruise or I couldn't go out when the sun is shining or if I miss my husband's voice and his laugh or even the silly discussions we used to have, I remind myself, my husband is his best self today and I should be thankful. I can hug him, hold his hands, he can write words for me then I make them into sentences until I get what he wants 😊, he can hold my hands when he can see I am upset, he sleeps better now than few weeks ago because of finally trying his CPAP machine at night. He gets anxious but he looks at me and after a few minutes I can see him getting better. Its one horrible day at a time now for us, but we have lots of moments where we smile at each other and I hope he doesn't feel alone in this, that he has me always.

I was overthinking last night about the future his future battles still to come and it really affected me.

And I go back to this group and lots of people are on the same boat as us, helping each other and making jokes and living, fighting this disease.

I just want to say to whoever reads this, you are AMAZING. My husband too...having to give me a smile every morning and precious moments ☺ that lasts forever xxx


Love to all, and have a great day *+fotografie*

7. (16. říjen 2021) What would you do?

A consistent home health aide is difficult to find. We have a consistent one for the most part, but after she changes my mom's diaper, she spends the rest of the time on her phone. My mom said she asked her all week to do her hair, but she didn't do it. She's here for 4 hours. She doesn't do jobs that are less than 6 hours, and she said the only reason that she took this assignment is because it's my mom. (She covered for another aide a while ago, so she was familiar). She hasn't changed my mom's linen either. I end up doing it. I want to say something to her and to the agency, but I'm afraid we'll get someone who shows up twice a week instead of 5 days per week. Should I let it be, or should I say something?

7. (9. leden 2022) Hello, please can I ask what do you use to keep your head up in a good position. I have bought a lot of neck braces from just like chin rest, discreet ones to a supplied by hospital bulky neck brace. My Pals husband rejects them as he feels like choking and don't like anything on his neck . I also bought a travel pillow or I use a rolled towel, he doesn't mind that but it doesn't stay in place for the whole night. I am out of ideas and it really bothers me to see his head down to his chest and complains that his neck is sore. What do you guys do? Thank you in advance x

8. (14. září 2021) My mom had slippers on and would not allow women to assist her with standing up. She would always be in a seated position with her legs spread out in front of her. Today we put sneakers on her and she stood right up. Now that my husband is home, she's claiming that she can't stand, and she wants him to help her. This woman is trying my patience. Lol!

8. (7. leden 2022) My husband giving me Love . Have a lovely morning Everybody from us here in Edinburgh Scotland. +*fotografie*

9. (31. srpen 2021) This was my mom in April 2020. Today, she cannot walk. Her last time walking unassisted was July 18th, 2021 when she was admitted in the hospital for breathing issues. She spent 2 weeks in the hospital in bed. She went to rehab for 20 days and was walking with assistance, and they even had her going up and down the stairs also with assistance. She came home on Aug 17th. She doesn't trust that I won't make her fall, so she won't try to walk. 🤔 She'll never walk again. It's so crazy how this disease takes away a piece of you on a monthly or weekly basis.
+video

9. (6. leden 2022) Hello, did anybody used a chiropractor and or acupuncture and felt the benefits especially in the neck area muscle control and pain with neck strain?

10. (20. srpen 2021) So the latest on my mom.... A week after her g-tube was pulled out by the Aide at rehab, she was discharged home. Two days later, she's back in the ER, because the foley catheter balloon went into her intestines. She is now admitted to the hospital to get the catheter replaced with a g-tube. This is what we've been fighting for since it was pulled out.
UPDATE: The g-tube has been replaced, and my mom is doing well. I'm not sure of when she'll be discharged though. 🤔🤔

10. (21. únor 2022)

Table 1. Properties of marijuana applicable to ALS symptom management	
ALS symptom	Marijuana effect
Pain	Nonopioid analgesia and anti-i
Spasticity	Muscle relaxant
Wasting	Appetite stimulant
Dyspnea	Bronchodilation
Drooling	Dry mouth
Depression	Euphoria
Dysautonomia	Vasodilation
Neuronal oxidation	Neuroprotective antiox

11. (14. srpen 2021) My mom is in rehab. She got her g-tube placed about 3 weeks ago. On Sunday, an Aide that was tending to her, pulled out her g-tube. Now she has a foley catheter in its place, and they won't replace the g-tube at the facility because it's less than 3 months old. I'm so pissed! The Aide claims when she pulled my Mom's gown back, the g-tube was laying there. My mom said the Aide did it, and said she was rough with her. My mom can't use her hands, so she didn't do it. Everyone else there agrees. She also has her faculties about her and knows what's going on. They are discharging her next week with this catheter instead. I'm not happy about this at all!

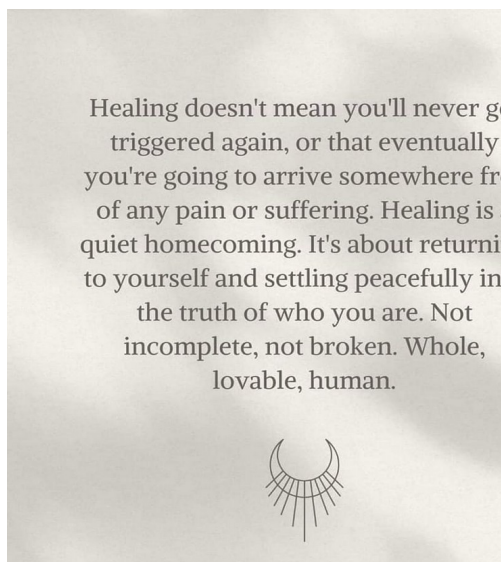
11. (4. únor 2022) Good day to all



12. (3. srpen 2021) G-tube question: Isn't the tube supposed to be clear of any liquids when feeding is complete? My mom's tube has water sitting in there, like it didn't go all the way down.

UPDATE: I watched my Mom's nurse plunge the food through the tube because it wouldn't go down. This doesn't seem right! Please tell me I'm wrong.

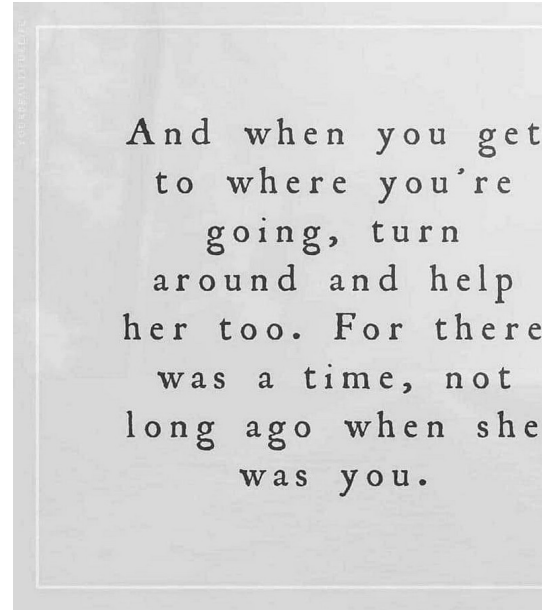
12. (17. leden 2022)



13. (26. červenec 2021) My mom is 86 and was diagnosed last **13. (17. leden 2022)**

May. Last Sunday she was rushed to the hospital due to her weezing. Since then she had a peg tube placed. She passed the barien swallow test, and was given the option to eat orally or via the tube. The next day she choked when fed orally, so she now has to be fed only by tube. Now she chokes even on her saliva, and goes into respiratory distress. Today she choked 3 times, and I was there for one episode. It was bad. I'm remaining positive, but realistically thinking, I don't know if she'll leave the hospital alive. She's supposed to go to rehab today, but I don't know. If she does, I don't think she'll come home. I've done everything that I can for her at this point.

😞😞



14. (19. červenec 2021) Do PALS generally develop asthma? **14. (15. leden 2022)**

My mom was rushed to the hospital because she was weezing uncontrollably. The doctor said she has asthma. My mom is 86 and never had it before.

Some days you will
The Cool Shady Tree
be the light for other
and some days you
will need some light
from them.
As long as there is
light there is hope
and there is a way

15. (20. květen 2021) A cup to help your PALS, to help prevent choking.

The Provale Cup is a Limited Flow Cup for the delivery of thin liquids.

https://www.amazon.com/dp/B00CZ3GGHG/ref=cm_sw_r_cp_awdb_imm_2DW1076CTW62HXX46KQT?_encoding=UTF8&psc=1&fbclid=IwAR2Z7odsDLdCbF-7_tyCvv6VzGSNizBAdncTUWWTiWwXMeG9_r_EQz4yFw

A curved spoon to help your PALS. -

https://www.amazon.com/dp/B07KLZVM7K/ref=cm_sw_r_cp_awdb_imm_K4GADMMQH01VHXVZX5PZ?_encoding=UTF8&psc=1&fbclid=IwAR1Aun7aqWnOGk_6iOMNqIV-XHa3M_a2RvWI999yxfbKS9R8L68pj_3vGNU

Pečovatel 5

18

Pečovatel (dcera)

1. (9. březen 2022) With hurricane season approaching I am looking for some backup battery alternatives for my mom's trilogy machine. Any suggestions? Paying \$14,000 for a generator is not feasible.

2. (25. listopad 2021) When do you know when to put someone on hospice? What are questions to ask? What are things I should know?

3. (10. listopad 2021) My mom has excessive burping. What can i do? Is this normal?

4. (12. červenec 2021) What is everyone using as a battery backup for the Trilogy machine. I am trying to prepare for hurricane season. Thanks.

5. (15. červen 2021) My mom has been feeling nauseous all day. She says she has to vomit but its only saliva coming up. Any suggestions? I don't know wgat to do 🙄

6. (25. duben 2021) My mom suddenly needs her trilogy more often. Is this normal?

7. (27. leden 2021) Is there anything that works fast for constipation? Sorry dont want to offend anyone 🙏

8. (15. listopad 2020) Any ideas how to get rid of a bedsore?

9. (12. říjen 2020) Has anyone used this to prevent pressure sores? Does it work?



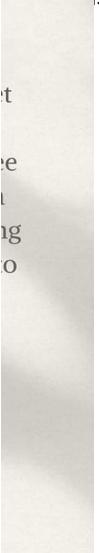
10. (4. září 2020) My mom said she has a sharp pain on her left side. Does anyone else experience these type of pains?

nflammatory
idant

11. (4. září 2020) Does anyone take blood thinners to prevent blood clots? The doctor said my mom needs them since she is



12. (26. srpen 2020) Better Days are Coming Pal and Cals. This



13. (26. srpen 2020) Am I the only one that has a hard time trying to get family or friends to understand my Pals condition? I feel like I am on repeat. I can't, I ain't, and I won't walk on the streets with you. All my time and energy is spent on my Pals. I don't mind taking care of my Pals. I would help others take care of their Pals. But what is hard is explaining to family and friends the same thing over and over. I am busy. My focus is my mom! That's it!

14. (25. srpen 2020) I remember one day I was pulling my mom (Pals) back on the bed and she was screaming because she thought she was going to fall. So I started screaming at her and she started crying. Of all of the 42 years I've been on this earth I have NEVER seen or heard my mom cry. She is the strongest person I know! From that moment my #1 goal was to make sure my mom is happy and in care of everyday. This is the purpose God has given me in this moment in my life. He has provided and will continue to provide whatever we need. No job or material things can replace the time I have here on this earth with my mom. All the caregivers stay strong and push through. Remember to take care of yourself also. Set time each day or week to do something for yourself and remember you are not alone. We are all in this together 😊

15. (25. srpen 2020) Pals and Cals when you feel discouraged and alone keep going ♥♥♥♥♥



16. (22. srpen 2020) Does medicare cover the cost of wheelchairs?

17. (28. červenec 2020) My mom was thinking about participating in a clinical trial? Has anyone tried this? What are your thoughts?

18. (27. červenec 2020) Hello. Thank you for allowing me to join. My mom was diagnosed in Jan/ February. Any suggestions on how to prevent bed sores?

Pečovatel 6

31

Pečovatel (dcera)

Celkový počet příspěvků:

Počet zkoumaných pečovatелů:

Počet zkoumaných pacientů:

1. (4. březen 2022) Dad can not hold his paperback books really anymore. Any ideas to help. He does not want them on a kindle he wants the paperback ones they are old westerns Also trouble holding small things to get a drink we use straws and hone his drinks but would sippy cup be easier

2. (2. března 2022) Dad is on the Bipap 24/7 he doesn't even want to take off to eat. He eats a pudding snack and that's about it. This disease is so brutal 🤔

3. (10. únor 2022) Anyone else PALS have upset tummy's for weeks in end? He hardly eats anymore. Nothing helps. 😊

4. (10. únor 2022) My dads been having pain in his tummy for days. The nurse had no clue. He potty's once a day when we go over to transfer. He feels horrible could it be something else? Anyone else have tummy trouble ??

5. (4. únor 2022) My dad says nothing taste good and seems like it has no flavor. Has anyone else experienced this perhaps?

6. (28. leden 2022) They dropped off the cough assist machine. But no one knew how to tell us to use it. The person that was suppose to show us is sick and could not show us. Dad tried it and started coughing so we took it off 😞anything we need to know? They said when someone is well they will send out.

7. (26. leden 2022) They delivered the suction machine but I was not here. He says it's not working. Is there a trick to this thing? He was putting it in his nose I though it was for back of throat.

8. (25. leden 2022) What can you get to help suck flem out of Pals throat?

9. (21. leden 2022) Dad just started oxygen but it makes his throat hurt. Is this normal? He is on level 2

10. (20. leden 2022) Dads heart rate is 114 doctors we called they said they would get him monitor. how can I help get it down? Think one of his doctors he spoke to today upset him and she was extremely hateful to him. I've been massaging him any other tips.

11. (10. leden 2022) Dad is horse today and said having trouble breathing. 🤔😬 is this because he is losing voice? He has an appointment in May to see pulmary specialist. That is forever wait 😬

12. (7. leden 2022) Dad has been drinking protein shakes like boost but it's giving him gas. Is there any other high protein recommendations? He is only able to drink right now.

13. (7. leden 2022) Can you get bed rails without having a hospital bed. We are getting conflicting answers from all the different therapist that come over.

14. (5. leden 2022) Help....dad is getting harder and harder to transfer as he declines.. the PT can't even get him on potty potty with the hoyer? 😊 any ideas how to make using the potty not so hard. I'm about to cry listening to him.

15. (1. leden 2022) We can not find anyone for lift help. The hoyer will not work on the carpet and VA has not pulled it up yet. Checked several places and no one does lift help. Any help appreciated. It's getting harder and harder to lift him.

16. (22. prosinec 2021) There is no off button for hoyer
It's a hoyer advance 340
Does not work on our rugs 😞but need it off

17. (8. prosinec 2021) My dad can't sleep and said he is in so much pain in his legs anything and he has to pee every hour is this normal ?

18. (23. listopad 2021) Going to pick up hoyer for parents but my sister mentioned the low bed and thick carpet may hinder using it. At least in that room. Ideas?? Thoughts?

19. (11. listopad 2021) Has anything helped your PALS with swollen ankles. Compression socks have not helped very much.

20. (10. listopad 2021) My parents went to the doctor and they were no help! They asked about a hooyer to lift him and they dismissed it. Said it was big and bulky. My mom can not lift him. Don't know what to do. We need something skinny to get through doors. The transport will not fit the wheelchair will not fit 😞😞😞no construction on there bath room is even close said it's months away

21. (7. listopad 2021) What is the easiest way to travel? My dad wanted to make it to Oregon so he will have been to all 50 states. Now that he is in a wheelchair and things are moving faster than we thought.

22. (31. říjen 2021) I tried it first to make sure he won't fall. This is not working at all 😊😊How do you get from wheelchair to car ? *+fotografie*

23. (31. říjen 2021) My dad keeps falling. When he tries to transfer from certain places. He has hurt he ankles and knees. I don't know what to do to help my parents ☹️usually transfer chair it potty ☹️he can't fit in the rooms of the house with the wheelchair so has to use the walker

24. (18. říjen 2021) Updated
Someone from this group reached out and gave me a cell number to the chapter and I was able to talk to someone. They are not at the office right now due to Covid.
I have reached out numerous time to the ALS chapter to get help and no one calls me back ever. Is this typical ?

25. (15. říjen 2021) My dad wants to take my son hunting one last time. He knows he can't be in the woods with him so he will stay back at veh. Please give me pointers on how to get him in the truck with no use of his legs. His friend is taking my dad and son. Any ideas are appreciated

26. (8. říjen 2021) My dad is having a hard time taking a shower and is in a wheelchair my mom is little and there is a small lip on the shower. It's slipper on the shower is there any pointers till they can get the shower redone on how to transfer in the shower

27. (2. říjen 2021) Have an appointment with 2nd MD tomorrow what questions should we ask?

28. (2. říjen 2021) My daddy's legs no longer work but he tries so hard to keep just using the walker. He lifts weights with his arms as he still has strength in them. Question is it hurting him pushing himself. He's afraid if he stops trying that it will go faster. He worked out 2 hours everyday for 30 plus years???

29. (30. říjen 2021) The just put my dad on Rilutek but none of the pharmacy's have it. They are trying to get it anyone else have this issue? What do you think of this drug and why can't they seem to get it.

30. (29. září 2021) My dad has always had trouble sleeping but since the diagnoses neither of my parents can sleep. What have you seen help?

31. (21. září 2021) My dad goes to his first appointment on the 28th after getting the diagnoses over the phone. What should we expect and any questions that need to be asked we might not have thought of? I saw there are different types. How do they no if yours is slow or a faster progression? Thanks for any advice.

193

6

4

	Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Pacient 1	Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	131
	Text	Výpověď	Návštevy lékaře, prohlídky, operace	116
	Text a multimédia	Výpověď	Sociální skupiny a jiné společenské akce	287
	Text a multimédia	Výpověď	Motivování ostatních členů skupiny	302
	Text a multimédia	Výpověď	Zábava	466
	Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	122
	Text a multimédia	Výpověď	Motivování ostatních členů skupiny	190
	Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	248
	Text a multimédia	Výpověď	Péče o zdraví, prevence	85
	Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	333
	Text a multimédia	Motivace a pobavení	Zábava	58
	Text a multimédia	Výpověď	Zábava	76
	Text a multimédia	Výpověď	Péče o zdraví, prevence	351
	Text a multimédia	Motivace a pobavení	Kvalita zdravotnických služeb	313
	Text a multimédia	Doporučení	Péče o zdraví, prevence	47

Text a multimédia	Výpověď	Pohyb a přemísťování (v domácnosti)	403
Text, multimédia a odkaz	Doporučení	Pomůcky	224
Text a multimédia	Výpověď	Pozitivní události	96
Text a multimédia	Výpověď	Pohyb a přemísťování (v domácnosti)	162
Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	245
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	563
Text a multimédia	Výpověď	Pomůcky	148
Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	337
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	180
Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	189
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	42
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	209
Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	284
Text a multimédia	Kombinace	Motivování ostatních členů skupiny	343
Text a multimédia	Výpověď	Péče o zdraví, prevence	384
Text a multimédia	Kombinace	Stravování	236
Text a multimédia	Výpověď	Stravování	13
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	48
Text a multimédia	Výpověď	Pomůcky	24
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	281

	Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	146
Pacient 2	Text	Motivace a pobavení	Péče o zdraví, prevence	12
				79
	Text	Výpověď	Motivování ostatních členů skupiny	25
	Text	Výpověď	Přemístování (mimo domácnost)	85
	Text	Výpověď	Zábava	28
	Text	Výpověď	Myšlenky, psychologie	37
	Text a multimédia	Výpověď	Myšlenky, psychologie	138
	Text	Výpověď	Oblékání	17
	Text	Výpověď	Stárnutí a umírání	195
	Text	Výpověď	Výběr pečovatелů a zdravotnických zařízení	24
	Text	Doporučení	Myšlenky, psychologie	27
	Text	Motivace a pobavení	Motivování ostatních členů skupiny	35
	Text	Výpověď	Osobní hygiena	232
	Text a multimédia	Výpověď	Výběr pečovatелů a zdravotnických zařízení	30
	Text a multimédia	Výpověď	Přemístování (mimo domácnost)	108
	Text a multimédia	Výpověď	Sociální skupiny a jiné společenské akce	259
	Text	Motivace a pobavení	Motivování ostatních členů skupiny	24
	Text	Výpověď	Sociální skupiny a jiné společenské akce	159
	Text	Výpověď	Motivování ostatních členů skupiny	

	Text	Výpověď	Předání osobních informací	110
	Text a multimédia	Výpověď	Předání osobních informací	487
Pečovatel 1	Text	Výpověď	Stárnutí a umírání	194
	Text	Výpověď	Změna zdravotního stavu pacienta	166
	Text	Výpověď	Změna zdravotního stavu pacienta	106
	Text	Dotaz	Vyhledání pomoci	0
	Text	Dotaz	Pomůcky	14
	Text	Dotaz	Péče o zdraví, prevence	10
	Text	Dotaz	Změna zdravotního stavu pacienta	5
	Text	Motivace a pobavení	Zábava	126
	Text	Výpověď	Výběr pečovatelů a zdravotnických zařízení	60
	Text	Výpověď	Pozitivní události	161
Pacient 3	Text a multimédia	Motivace a pobavení	Zábava	1427
	Text a multimédia	Motivace a pobavení	Pomůcky	159
	Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	390
	Text a multimédia	Výpověď	Pomůcky	314
	Text a multimédia	Motivace a pobavení	Zábava	103
	Text a multimédia	Doporučení	Pomůcky	230
	Text a multimédia	Motivace a pobavení	Zábava	133
	Text	Kombinace	Užívání léků	8
	Text a multimédia	Výpověď	Zábava	191
	Text a multimédia	Výpověď	Zábava	230
	Text	Kombinace	Pomůcky	1
	Text	Kombinace	Pomůcky	0
	Text	Doporučení	Péče o zdraví, prevence	27
	Text	Výpověď	Změna zdravotního stavu pacienta	32
	Text	Výpověď	Uklízení a udržování domácnosti	117
	Text	Výpověď	Stravování	8
	Text	Kombinace	Užívání léků	1
	Text a multimédia	Výpověď	Zábava	445
	Text a multimédia	Motivace a pobavení	Zábava	108
	Text a multimédia	Doporučení	Pomůcky	10
	Text a multimédia	Výpověď	Užívání léků	31
	Text a multimédia	Doporučení	Pomůcky - toaleta	126

Pečovatel 2	Text	Kombinace	Vyhledání pomoci	0	
	Text	Dotaz	Užívání léků	0	
	Text	Dotaz	Pomůcky	1	
	Text	Kombinace	Změna zdravotního stavu pacienta	8	
	Text	Kombinace	Stravování	8	
	Text	Dotaz	Výběr pečovatelů a zdravotnických zařízení	3	
	Text	Kombinace	Výběr pečovatelů a zdravotnických zařízení	7	
	Text	Dotaz	Kvalita zdravotnických služeb	7	
	Text	Dotaz	Pomůcky	3	
	Text	Dotaz	Vyhledání pomoci	5	
	Text	Kombinace	Negativní pocity pečovatele	19	
	Text	Kombinace	Nespavost a poruchy nočního chování	0	
	Text	Kombinace	Nespavost a poruchy nočního chování	20	
	Text	Dotaz	Péče o zdraví, prevence	4	
	Text	Dotaz	Vyhledání pomoci	5	
	Pečovatel 3	Text	Výpověď	Vděčnost za existenci skupiny a poskytnuté rady, podporu	241
		Text	Výpověď	Předání osobních informací	84
Text		Výpověď	Příznaky	118	
Text a multimédia		Výpověď	Stárnutí a umírání	576	
Text		Kombinace	Péče o zdraví, prevence	185	
Text		Výpověď	Změna zdravotního stavu pacienta	133	
Text		Kombinace	Výběr pečovatelů a zdravotnických zařízení	19	
Text		Výpověď	Zábava	18	
Text a multimédia		Výpověď	Změna zdravotního stavu pacienta	112	
Text		Výpověď	Změna zdravotního stavu pacienta	41	
Text		Výpověď	Stravování	61	
Text		Dotaz	Stravování	3	

	Text	Výpověď	Změna zdravotního stavu pacienta	40
	Text	Dotaz	Změna zdravotního stavu pacienta	19
	Text a odkaz	Doporučení	Pomůcky	2
Pečovatel 4	Text a multimédia	Dotaz	Pomůcky	3
	Text	Kombinace	Pomůcky	2
	Text	Výpověď	Strach z budoucnosti	675
	Text	Kombinace	Užívání léků	7
	Text a multimédia	Dotaz	Pomůcky	40
	Text a multimédia	Výpověď	Myšlenky, psychologie	524
	Text	Kombinace	Pomůcky	10
	Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	882
	Text	Dotaz	Vyhledání pomoci	1
	Pouze multimédia	Doporučení	Příznaky	47
	Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	209
	Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	58
	Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	176
	Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	242
Pacient 4	Text a multimédia	Motivace a pobavení	Zábava	35
	Text a multimédia	Výpověď	Vděčnost za existenci skupiny a poskytnuté rady, podporu	360
	Text	Výpověď	Motivování ostatních členů skupiny	76
	Text a multimédia	Motivace a pobavení	Zábava	340
	Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	125
	Text a multimédia	Motivace a pobavení	Vděčnost za existenci skupiny a poskytnuté rady, podporu	60
	Text a multimédia	Motivace a pobavení	Zábava	223
	Pouze multimédia	Motivace a pobavení	Zábava	36
	Text a multimédia	Motivace a pobavení	Zábava	389
	Text, multimédia a odkaz	Výpověď	Pozitivní události	99
	Pouze multimédia	Motivace a pobavení	Zábava	81
	Text a multimédia	Výpověď	Motivování ostatních členů skupiny	221
Pečovatel 5	Text	Dotaz	Bezpečnostní opatření	1

Text	Dotaz	Vyhledání pomoci	4
Text	Kombinace	Péče o zdraví, prevence	0
Text	Dotaz	Bezpečnostní opatření	0
Text	Kombinace	Změna zdravotního stavu pacienta	0
Text	Dotaz	Změna zdravotního stavu pacienta	1
Text	Dotaz	Péče o zdraví, prevence	20
Text	Dotaz	Pomůcky	7
Text a multimédia	Dotaz	Pomůcky	2
Text	Dotaz	Změna zdravotního stavu pacienta	0
Text	Dotaz	Užívání léků	4
Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	2
Text	Výpověď	Negativní pocity pečovatele	57
Text	Výpověď	Myšlenky, psychologie	181
Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	53
Text	Dotaz	Pomůcky	4
Text	Dotaz	Kvalita zdravotnických služeb	6
Text	Kombinace	Předání osobních informací	2
Pečovatel 6	Kombinace	Pomůcky	20
Text	Výpověď	Stravování	115
Text	Dotaz	Stravování	16
Text	Kombinace	Příznaky	12
Text	Kombinace	Příznaky	18
Text	Kombinace	Pomůcky	8
Text	Kombinace	Pomůcky	13
Text	Dotaz	Pomůcky	11
Text	Kombinace	Pomůcky	5
Text	Kombinace	Péče o zdraví, prevence	16
Text	Kombinace	Změna zdravotního stavu pacienta	10
Text	Kombinace	Stravování	5
Text	Dotaz	Pomůcky	8
Text	Kombinace	Pohyb a přemísťování (v domácnosti)	14

Text	Kombinace	Pohyb a přemístování (v domácnosti)	7
Text	Výpověď	Pohyb a přemístování (v domácnosti)	1
Text	Dotaz	Nespavost a poruchy nočního chování	6
Text	Kombinace	Pomůcky	2
Text	Kombinace	Péče o zdraví, prevence	2
Text	Výpověď	Pomůcky	31
Text	Kombinace	Přemístování (mimo domácnost)	1
Text a multimédia	Dotaz	Přemístování (mimo domácnost)	22
Text	Výpověď	Změna zdravotního stavu pacienta	3
Text	Kombinace	Výběr pečovatелů a zdravotnických zařízení	6
Text	Kombinace	Přemístování (mimo domácnost)	6
Text	Kombinace	Koupání a sprchování	6
Text	Dotaz	Návštěvy lékaře, prohlídky, operace	3
Text	Kombinace	Pohyb a přemístování (v domácnosti)	26
Text	Dotaz	Užívání léků	0
Text	Dotaz	Nespavost a poruchy nočního chování	1
Text	Kombinace	Návštěvy lékaře, prohlídky, operace	12

Finanční problémy	0
Hospodaření s penězi	0
Komunikace a interakce	0
Nakupování	0
Sport a podobné fyzické a	0
Svátky, narozeniny, výročí	0
Vaření, příprava jídel	0
Využívání komunikačních	0
<hr/>	
Koupání a sprchování	1
Oblékání	1
Osobní hygiena	1
Strach z budoucnosti	1
Toaleta	1
Uklízení a udržování domá	1
Bezpečnostní opatření	2

Negativní pocity pečovatelů	2
Kvalita zdravotnických služeb	3
Pozitivní události	3
Sociální skupiny a jiné společenství	3
Stárnutí a umírání	3
Vděčnost za existenci služby	3
Nespavost a poruchy nočního spánku	4
Předání osobních informací	4
Příznaky	4
Myšlenky, psychologie	5
Přemísťování (mimo domov)	5
Pohyb a přemísťování (v domě)	6
Vyhledání pomoci (v rodině)	6
Návštěvy lékaře, prohlídky	7
Užívání léků	7
Výběr pečovatelů a zdravotníků	7
Stravování	9
Péče o zdraví, prevence	13
Zábava	19
Motivování ostatních členů	21
Změna zdravotního stavu	23
Pomůcky	29

Aktivita	Počet příspěvků	Průměr reakcí	Průměr komentářů
Vyhledání pomoci (v rodině)	6	2,50	11,50
Užívání léků	7	7,29	21,14
Přemísťování (mimo domov)	5	16,80	14,80
Pomůcky	29	49,03	27,69
Stravování	9	51,67	33,00
Výběr pečovatelů a zdravotníků	7	74,57	37,29
Péče o zdraví, prevence	13	87,92	31,08
Změna zdravotního stavu	23	98,57	29,87
Pohyb a přemísťování (v domě)	6	102,17	39,00
Myšlenky, psychologie	5	158,80	33,00
Návštěvy lékaře, prohlídky	7	163,71	49,29
Motivování ostatních členů	21	216,43	25,81
Zábava	19	240,53	25,47

Aktivita	Počet příspěvků	Průměr reakcí	Průměr komentářů
Vyhledání pomoci (v rodině)	6	2,50	11,50
Přemísťování (mimo domov)	5	16,80	14,80
Užívání léků	7	7,29	21,14
Zábava	19	240,53	25,47
Motivování ostatních členů	21	216,43	25,81
Pomůcky	29	49,03	27,69
Změna zdravotního stavu	23	98,57	29,87
Péče o zdraví, prevence	13	87,92	31,08
Stravování	9	51,67	33,00

Myšlenky, psychologie	5	158,80	33,00
Výběr pečovatelů a zdravotníků	7	74,57	37,29
Pohyb a přemísťování (v domě)	6	102,17	39,00
Návštěvy lékaře, prohlídky	7	163,71	49,29

CELEK

Pomůcky	29
Změna zdravotního stavu	23
Motivování ostatních členů	21
Zábava	19
Péče o zdraví, prevence	13
Stravování	9
Návštěvy lékaře, prohlídky	7
Užívání léků	7
Výběr pečovatelů a zdravotníků	7
Pohyb a přemísťování (v domě)	6
Vyhledání pomoci (v rodině)	6
Myšlenky, psychologie	5
Přemísťování (mimo domov)	5
Nespavost a poruchy nočního spánku	4
Předání osobních informací	4
Příznaky	4
Kvalita zdravotnických služeb	3
Pozitivní události	3
Sociální skupiny a jiné společnosti	3
Stárnutí a umírání	3
Vděčnost za existenci skupiny	3
Bezpečnostní opatření	2
Negativní pocity pečovatelského týmu	2
Oblékání	1
Osobní hygiena	1
Strach z budoucnosti	1
Toaleta	1
Uklízení a udržování domova	1
Koupání a sprchování	1

Počet příspěvků - pacient

Bezpečnostní opatření	0
Finanční problémy	0
Hospodaření s penězi	0
Komunikace a interakce (s ostatními)	0
Koupání a sprchování	0
Kvalita zdravotnických služeb	1
Motivování ostatních členů	14
Myšlenky, psychologie	3
Nakupování	0

Počet příspěvků

Bezpečnostní opatření	2
Finanční problémy	0
Hospodaření s penězi	0
Komunikace a interakce (s ostatními)	0
Koupání a sprchování	1
Kvalita zdravotnických služeb	2
Motivování ostatních členů	7
Myšlenky, psychologie	2
Nakupování	0

Návštěvy lékaře, prohlídk	5	Návštěvy lékaře, prohlídk	2
Negativní pocity pečovate	0	Negativní pocity pečovate	2
Nespavost a poruchy noči	0	Nespavost a poruchy noči	4
Oblékání	1	Oblékání	0
Osobní hygiena	1	Osobní hygiena	0
Péče o zdraví, prevence	6	Péče o zdraví, prevence	7
Pohyb a přemísťování (v	2	Pohyb a přemísťování (v	4
Pomůcky	10	Pomůcky	19
Pozitivní události	2	Pozitivní události	1
Předání osobních informa	2	Předání osobních informa	2
Přemísťování (mimo dom:	2	Přemísťování (mimo dom:	3
Příznaky	0	Příznaky	4
Sociální skupiny a jiné sp	3	Sociální skupiny a jiné sp	0
Sport a podobné fyzické a	0	Sport a podobné fyzické a	0
Stárnutí a umírání	1	Stárnutí a umírání	2
Strach z budoucnosti	0	Strach z budoucnosti	1
Stravování	3	Stravování	6
Svátky, narozeniny, výročí	0	Svátky, narozeniny, výročí	0
Toaleta	1	Toaleta	0
Uklízení a udržování doma:	1	Uklízení a udržování doma:	0
Užívání léků	3	Užívání léků	4
Vaření, příprava jídel	0	Vaření, příprava jídel	0
Vděčnost za existenci sku	2	Vděčnost za existenci sku	1
Výběr pečovatelů a zdrav	2	Výběr pečovatelů a zdrav	5
Vyhledání pomoci (v rodin	0	Vyhledání pomoci (v rodin	6
Využívání komunikačních	0	Využívání komunikačních	0
Zábava	17	Zábava	2
Změna zdravotního stavu	9	Změna zdravotního stavu	14

Počet komentářů**DLE TYPU**

23	Počet pouze textových příspěvků	112
37	Počet příspěvků "text a multimedia"	69
44	Počet příspěvků s odkazem	3
30	Počet příspěvků "pouze multimedia"	9

DLE DRUHU OBSAHU

Počet výpovědí
Počet dotazů
Počet kombinací (výpověď + dotaz)
Počet doporučení
Počet "motivace a pobavení"

23

37

44

30

71

22

24

75

DLE RÁMCE ADLs

16	Základní denní aktivity	19
77	Instrumentální denní aktivity	32
2	Ostatní instrumentální denní aktivity	49
11	Specifické aktivity	94

16

77

2

11

44

41

STATISTIKY PŘÍSPĚVKŮ

3	Celkový počet příspěvků	193
---	-------------------------	-----

3

DLE JEDNOTLIVÝCH AKTIVIT (ADLs)

Koupání a sprchování
Osobní hygiena
Oblékání
Toaleta
Pohyb a přemísťování (v domácnosti)
Stravování
Komunikace a interakce (z očí do očí)

Koupání a sprchování

Osobní hygiena

Oblékání

Toaleta

Pohyb a přemísťování (v domácnosti)

Stravování

Komunikace a interakce (z očí do očí)

41	Celkový počet reakcí	22139
33	Celkový počet komentářů	5756
11	Průměrný počet reakcí	114,71
17	Průměrný počet komentářů	29,82

38
119
17
59
38
43
71
32
35
64
71
36
9
11
19
66

Uklízení a udržování domácnosti
Hospodaření s peněži
Přemísťování (mimo domácnost)
Vaření, příprava jídel
Nakupování
Užívání léků
Využívání komunikačních prostředků
Zábava
Sport a podobné fyzické aktivity

Výběr pečovatelů a zdravotnických zařízení
Příznaky
Bezpečnostní opatření
Nespavost a poruchy nočního chování
Svátky, narozeniny, výročí
Péče o zdraví, prevence
Sociální skupiny a jiné společenské akce
Stárnutí a umírání
Vyhledání pomoci (v rodině i mimo)

18

Návštěvy lékaře,
prohlídky, operace

0

11

Kvalita
zdravotnických služeb

1

Změna zdravotního
stavu pacienta

12

Negativní pocity
pečovatele (vína,
vyčerpání, ztráta
motivace)

1

Strach z budoucnosti

0

Pozitivní události

31

Finanční problémy

0

Vděčnost za existenci
skupiny a poskytnuté
rady, podporu

5

Motivování ostatních
členů skupiny

2

Pomůcky

2

Myšlenky,
psychologie

6

Předání osobních
informací

34

1

27

Poměr reakcí / komentářů

41

Zábava

0

Motivování ostatních členů skupiny

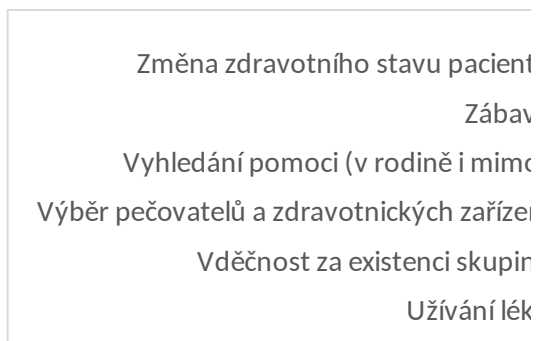
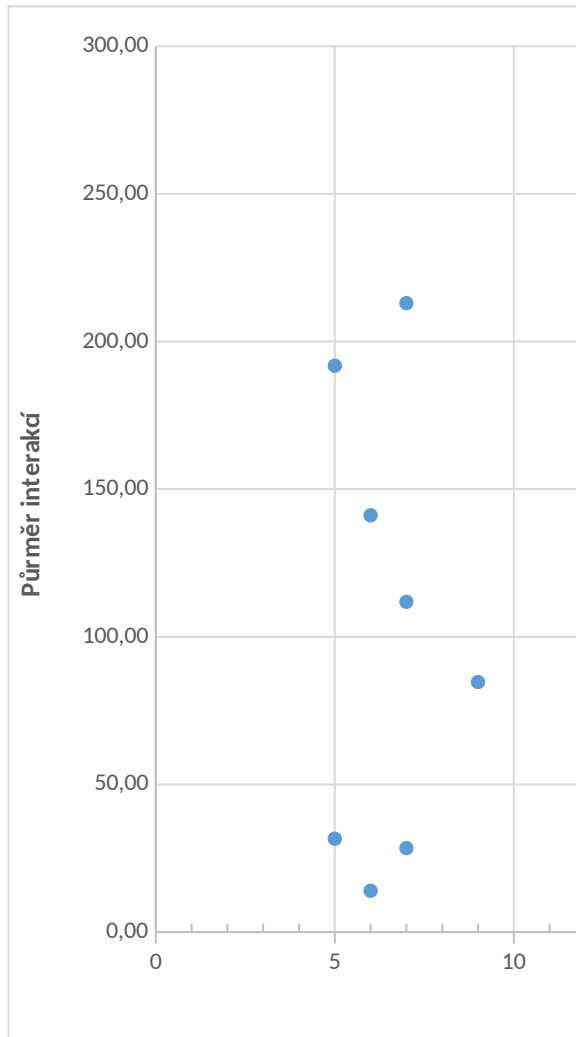
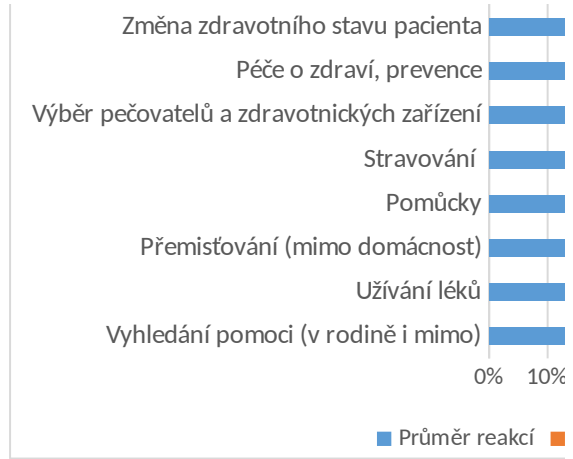
Návštěvy lékaře, prohlídky, operace

31

Myšlenky, psychologie

Pohyb a přemísťování (v domácnosti)

19
111
<hr/>
61
42
33
5
43
53
23
30
52
26
<hr/>
102
6
29
29
7
32
9
13
30
22
9
1
7
6
15
9
0
44
32
7
13
50
<hr/>



15
9
0
34
62
12
71
20
19
13
27
0
70
13
4

33
24
9
212
55
29
54
5
27
10
64
20

Uklízení a udržování domácnos
Toalet
Stravovár
Strach z budoucnos
Stárnutí a umírání
Sociální skupiny a jiné společenské akc
Příznak
Přemísťování (mimo domácnos
Předání osobních informa
Pozitivní událos
Pomůck
Pohyb a přemísťování (v domácnos
Péče o zdraví, prevenc
Osobní hygien
Obléká
Nespavosť a poruchy nočního chová
Negativní pocity pečovate
Návštěvy lékaře, prohlídky, operac
Myšlenky, psycholog
Motivování ostatních členů skupin
Kvalita zdravotnických službe
Koupání a sprchová
Bezpečnostní opatření

■ Počet

12

26

0

10

33

138

58

87

128

25

91

5

14

6

1

4

10

6

76

10

23

15

6

18

8

46

6

6

56

10

27

10

19

9

10

77

60

7

2

24

0

24

34

0

31

10

12

15

34

48

39

23

45

46

21

8

40

19

15

43

79

48

3

23

16

15

91

13

54

28

33

5

51

19

46

31

5

56

ářů

Počet interakcí (součet reakcí a komentářů)

14,00

28,43

31,60

76,72

84,67

111,86

119,00

128,43

141,17

191,80

213,00

242,24

266,00

ářů

- pečovatel

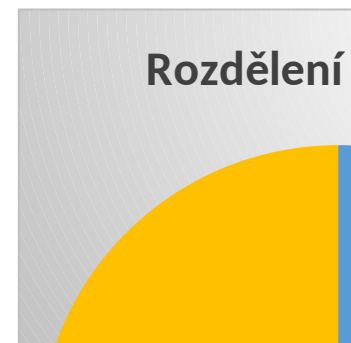
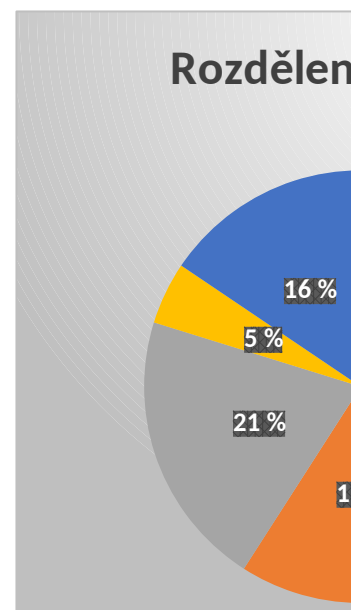
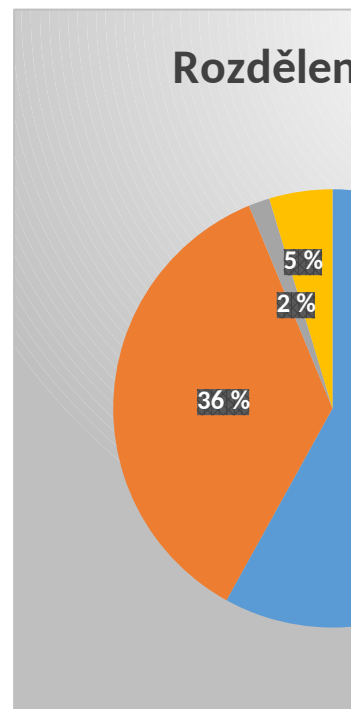
Pacient

78
36
40
9
30

Průměrný počet reakcí	176,99
Průměrný počet komentářů	27,23

Pečovatel

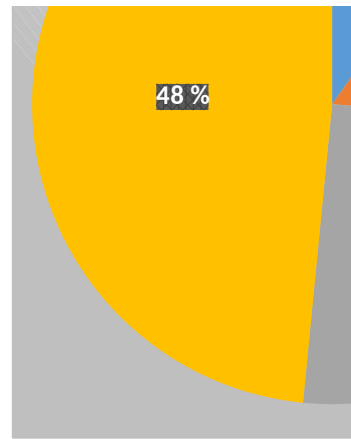
Průměrný počet reakcí	60,29
Průměrný počet komentářů	32,09



	Průměr reakcí	Průměr komentářů
1		
1		
1		
1		
6	102,17	39
9	51,67	33
0		

1		
0		
5	16,80	14,8
0		
0		
7	7,29	21,14
0		
19	240,53	25,47
0		

7	74,57	37,29
4		
2		
4		
0		
13	87,92	31,08
3		
3		
6	2,50	11,50



Počet přísp

Změna zdr
Motivování

Výběr pečovatelů a

Návštěvy lé
Vyhledání p
Pohyb a přer
Přemísťo

Pře
Nespavost a
Vděčnost za existenci skupiny a p

Sociální skupiny

Kvalit
Neg

Uklízení

Průměrr

.....

7	163,71	49,29
3		
23	98,57	29,87
2		
1		
3		
0		
3		
21	216,43	25,81
29	49,03	27,69
5	158,80	33,00
4		

Motivování ostatních
 Návštěvy lékaře, pro
 Myšle
 Pohyb a přemístování
 Změna zdravotní
 Péče o
 Výběr pečovatелů a zdravc

Přemístování (n

Vyhledání pomoci (

Průměrný

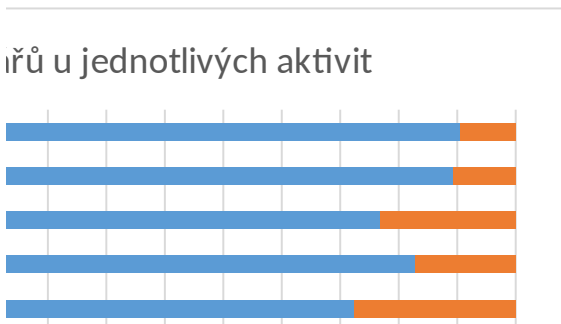
Návštěvy lékaře, proh
 Pohyb a přemístování (

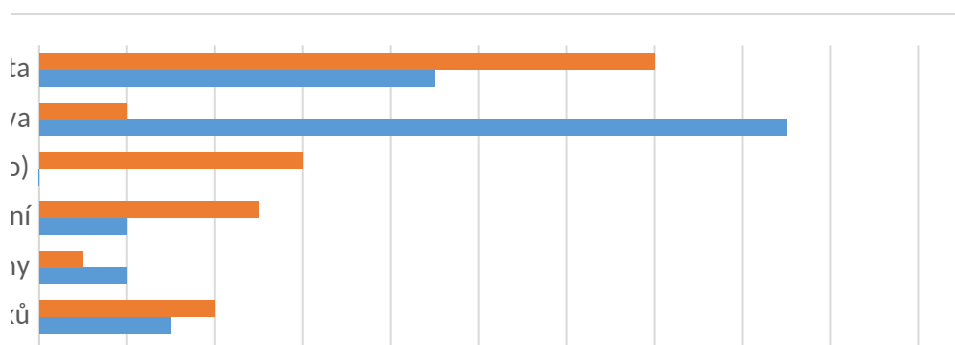
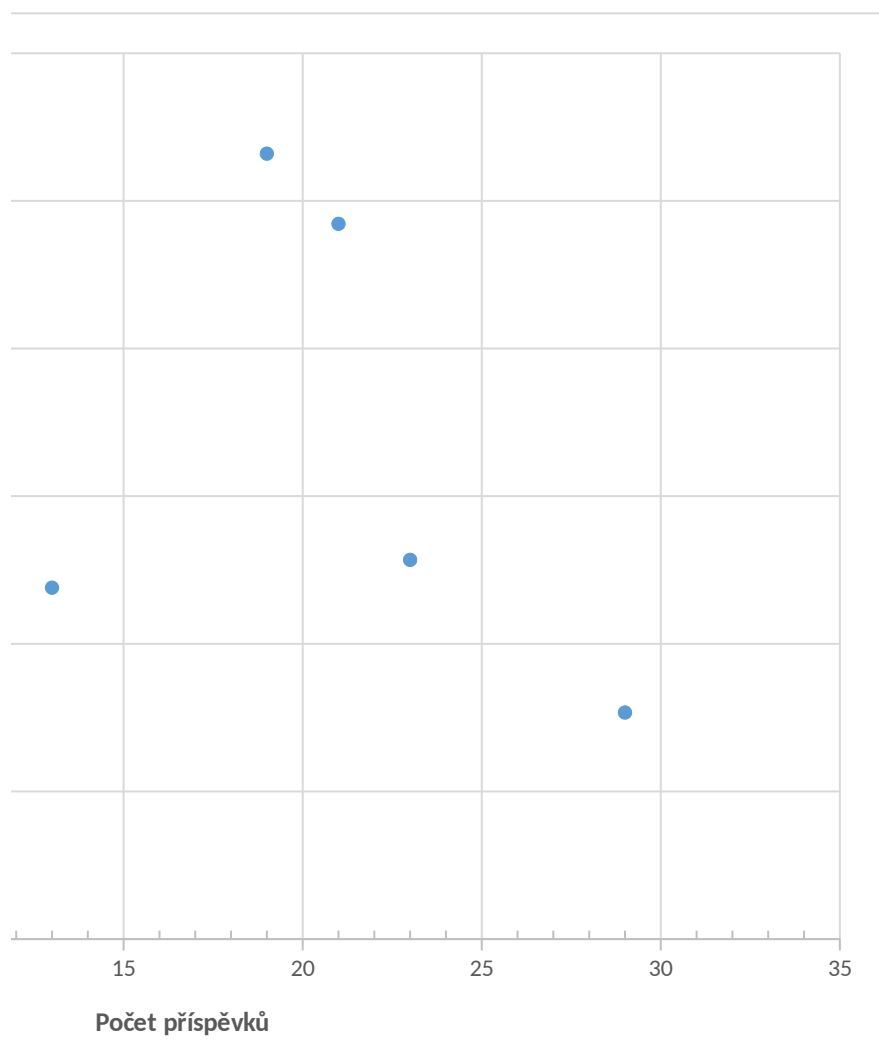
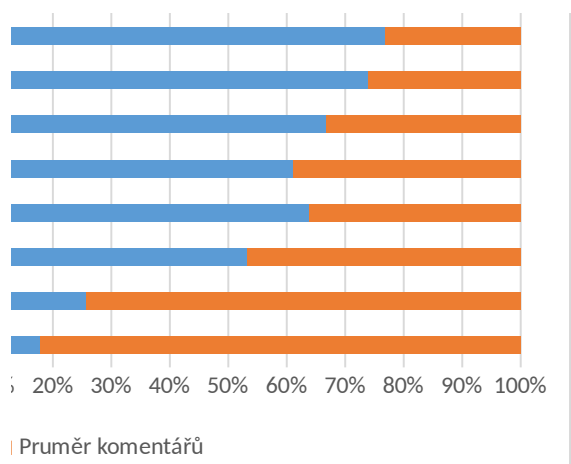
Výběr pečovatелů a zdravotni
 Myšlenk

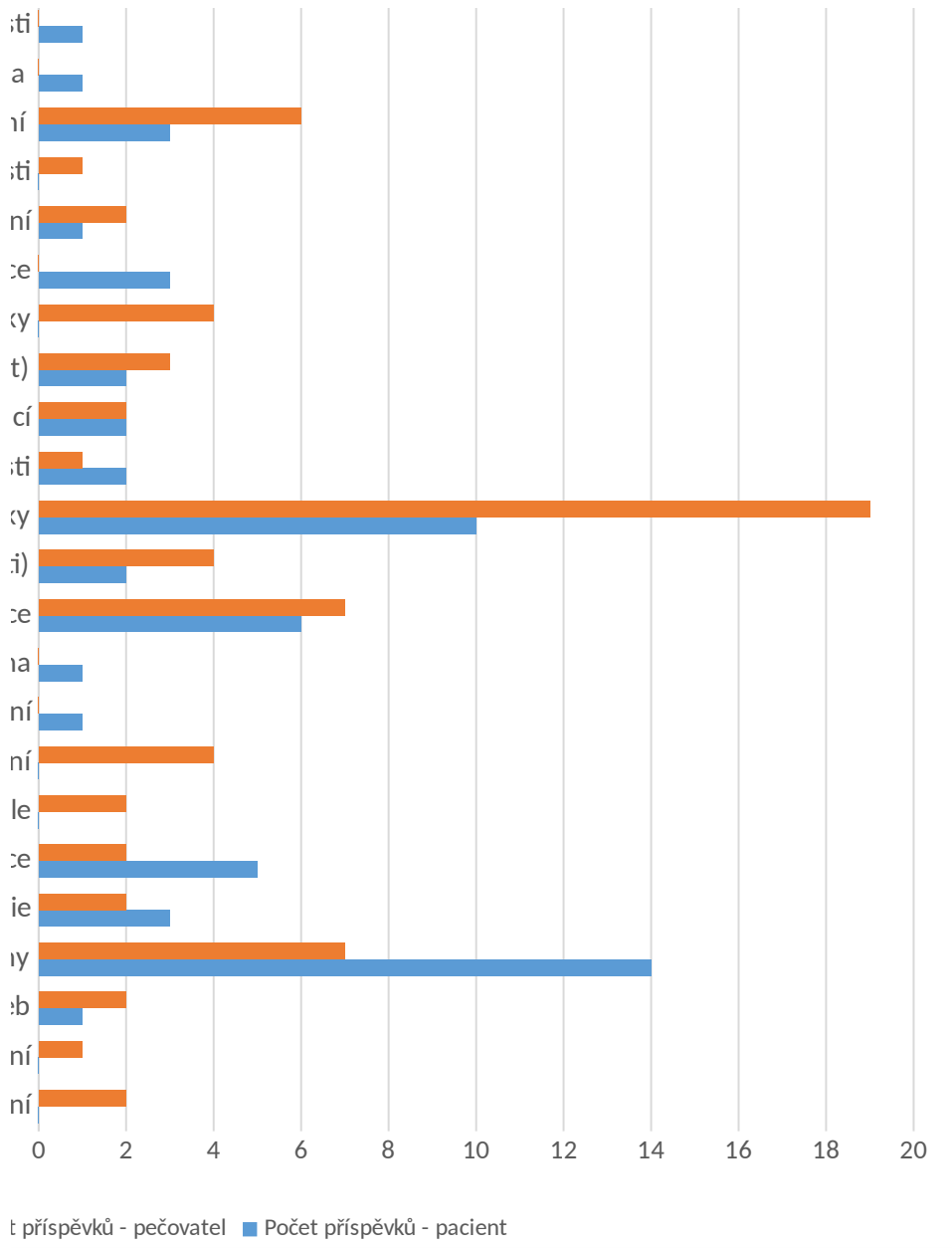
Péče o zd
 Změna zdravotního :

Motivování ostatních

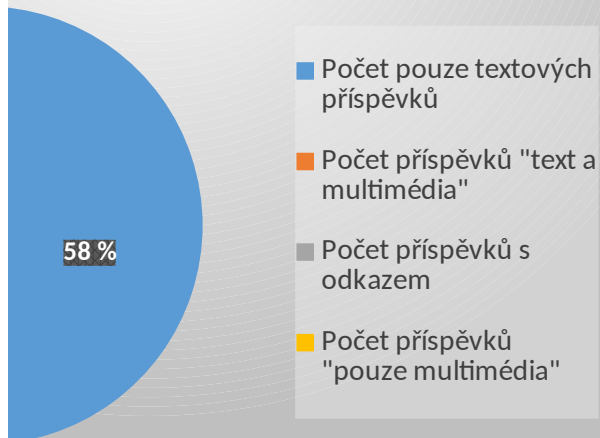
Přemístování (mir
 Vyhledání pomoci (v r



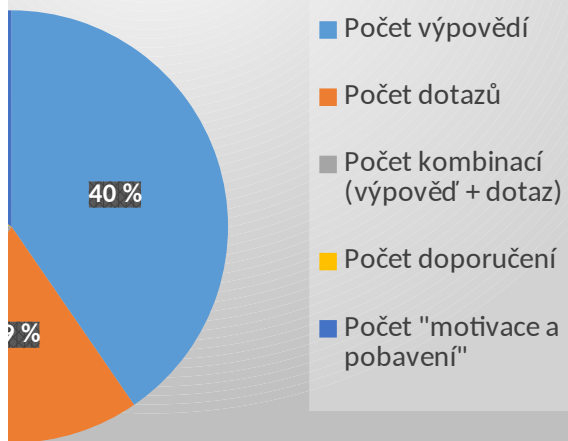




í příspěvků podle typu

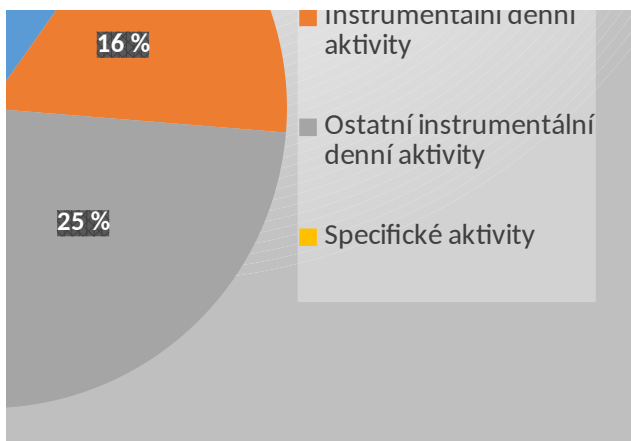


í příspěvků podle druhu obsahu

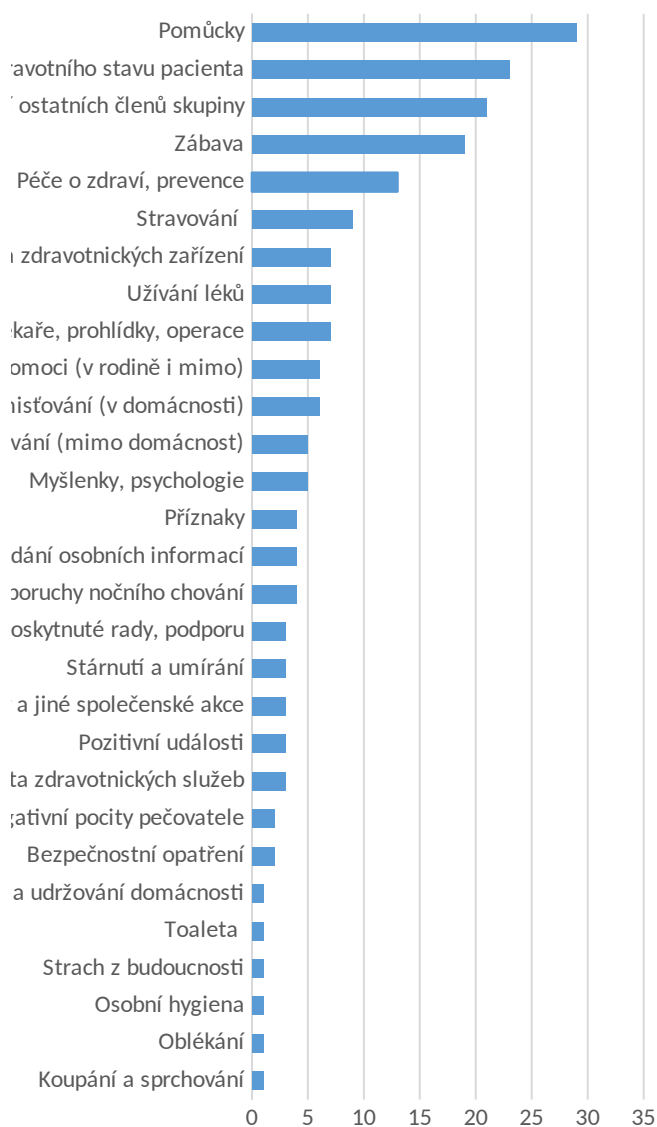


příspěvků do rámců ADLs



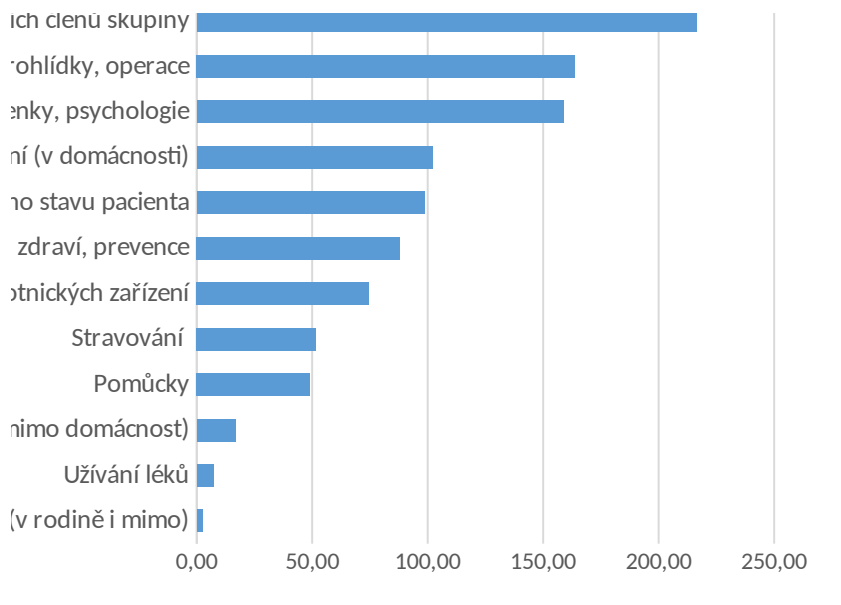


Poděvků jednotlivých kategorií ADLs

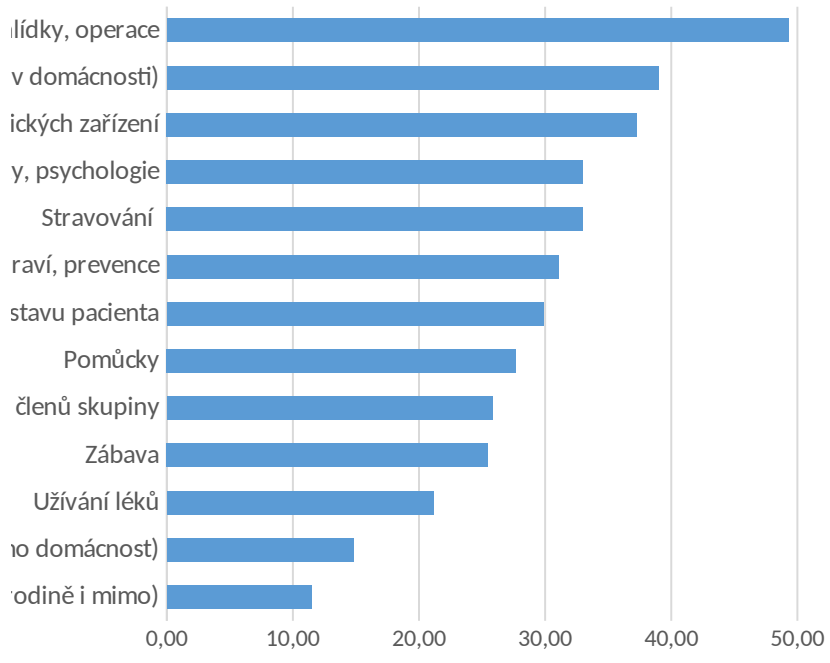


Nejvyšší počet reakcí u jednotlivých aktivit ADLs





počet komentářů u jednotlivých aktivit ADLs



	Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Pacient 1	Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	131
	Text	Výpověď	Návštěvy lékaře, prohlídky, operace	116
	Text a multimédia	Výpověď	Sociální skupiny a jiné společenské akce	287
	Text a multimédia	Výpověď	Motivování ostatních členů skupiny	302
	Text a multimédia	Výpověď	Zábava	466
	Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	122
	Text a multimédia	Výpověď	Motivování ostatních členů skupiny	190
	Text a multimédia	Výpověď	Návštěvy lékaře, prohlídky, operace	248
	Text a multimédia	Výpověď	Péče o zdraví, prevence	85
	Text a multimédia	Výpověď	Návštěvy lékaře, prohlídky, operace	333
	Text a multimédia	Motivace a pobavení	Zábava	58
	Text a multimédia	Výpověď	Zábava	76
	Text a multimédia	Výpověď	Péče o zdraví, prevence	351

Text a multimédia	Motivace a pobavení	Kvalita zdravotnických služeb	313
Text a multimédia	Doporučení	Péče o zdraví, prevence	47
Text a multimédia	Výpověď	Pohyb a přemísťování (v domácnosti)	403
Text, multimédia a odkaz	Doporučení	Pomůcky	224
Text a multimédia	Výpověď	Pozitivní události	96
Text a multimédia	Výpověď	Pohyb a přemísťování (v domácnosti)	162
Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	245
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	563
Text a multimédia	Výpověď	Pomůcky	148
Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	337
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	180
Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	189
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	42
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	209
Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	284
Text a multimédia	Kombinace	Motivování ostatních členů skupiny	343

Text a multimédia	Výpověď	Péče o zdraví, prevence	384
Text a multimédia	Kombinace	Stravování	236
Text a multimédia	Výpověď	Stravování	13
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	48
Text a multimédia	Výpověď	Pomůcky	24
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	281
Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	146

Pacient 2	Text	Motivace a pobavení	Péče o zdraví, prevence	12
	Text	Výpověď	Motivování ostatních členů skupiny	79
	Text	Výpověď	Přemísťování (mimo domácnost)	25
	Text	Výpověď	Zábava	85
	Text	Výpověď	Myšlenky, psychologie	28
	Text a multimédia	Výpověď	Myšlenky, psychologie	37
	Text	Výpověď	Oblékání	138
	Text	Výpověď	Stárnutí a umírání	17
	Text	Výpověď	Výběr pečovatelů a zdravotnických zařízení	195
	Text	Doporučení	Myšlenky, psychologie	24
	Text	Motivace a pobavení	Motivování ostatních členů skupiny	27

Text	Výpověď	Osobní hygiena	35
Text a multimédia	Výpověď	Výběr pečovatelů a zdravotnických zařízení	232
Text a multimédia	Výpověď	Přemísťování (mimo domácnost)	30
Text a multimédia	Výpověď	Sociální skupiny a jiné společenské akce	108
Text	Motivace a pobavení	Motivování ostatních členů skupiny	259
Text	Výpověď	Sociální skupiny a jiné společenské akce	24
Text	Výpověď	Motivování ostatních členů skupiny	159
Text	Výpověď	Předání osobních informací	110
Text a multimédia	Výpověď	Předání osobních informací	487

Pacient 3	Text a multimédia	Motivace a pobavení	Zábava	1427
	Text a multimédia	Motivace a pobavení	Pomůcky	159
	Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	390
	Text a multimédia	Výpověď	Pomůcky	314
	Text a multimédia	Motivace a pobavení	Zábava	103
	Text a multimédia	Doporučení	Pomůcky	230
	Text a multimédia	Motivace a pobavení	Zábava	133
	Text	Kombinace	Užívání léků	8
	Text a multimédia	Výpověď	Zábava	191
	Text a multimédia	Výpověď	Zábava	230
	Text	Kombinace	Pomůcky	1
	Text	Kombinace	Pomůcky	0

Text	Doporučení	Péče o zdraví, prevence	27
Text	Výpověď	Změna zdravotního stavu pacienta	32
Text	Výpověď	Uklízení a udržování domácnosti	117
Text	Výpověď	Stravování	8
Text	Kombinace	Užívání léků	1
Text a multimédia	Výpověď	Zábava	445
Text a multimédia	Motivace a pobavení	Zábava	108
Text a multimédia	Doporučení	Pomůcky	10
Text a multimédia	Výpověď	Užívání léků	31
Text a multimédia	Doporučení	Pomůcky - toaleta	126

Pacient 4

Text a multimédia	Motivace a pobavení	Zábava	35
			360
Text a multimédia	Výpověď	Vděčnost za existenci skupiny a poskytnuté rady, podporu	
Text	Výpověď	Motivování ostatních členů skupiny	76
Text a multimédia	Motivace a pobavení	Zábava	340
Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	125
Text a multimédia	Motivace a pobavení	Vděčnost za existenci skupiny a poskytnuté rady, podporu	60
Text a multimédia	Motivace a pobavení	Zábava	223
Pouze multimédia	Motivace a pobavení	Zábava	36
Text a multimédia	Motivace a pobavení	Zábava	389
Text, multimédia a odkaz	Výpověď	Pozitivní události	99
Pouze multimédia	Motivace a pobavení	Zábava	81

Text a multimédia	Výpověď	Motivování ostatních členů skupiny	
DLE JEDNOTLIVÝCH AKTIVIT (ADLs)		Průměr reakcí	Průměr komentářů
Koupání a sprchování	0		
Komunikace a interakce (z očí	0		
Hospodaření s penězi	0		
Vaření, příprava jídel	0		
Nakupování	0		
Využívání komunikačních pros	0		
Sport a podobné fyzické aktivi	0		
Příznaky	0		
Bezpečnostní opatření	0		
Nespavost a poruchy nočního	0		
Svátky, narozeniny, výročí	0		
Vyhledání pomoci (v rodině i	0		
Negativní pocity pečovatele (v	0		
Strach z budoucnosti	0		
Finanční problémy	0		
Osobní hygiena	1		
Oblékání	1		
Toaleta	1		
Uklízení a udržování domácnc	1		
Stárnutí a umírání	1		
Kvalita zdravotnických služeb	1		
Pohyb a přemísťování (v dom:	2		
Přemísťování (mimo domácnc	2		
Výběr pečovatelů a zdravotnic	2		
Pozitivní události	2		
Vděčnost za existenci skupiny	2		
Předání osobních informací	2		
Stravování	3		
Užívání léků	3		
Sociální skupiny a jiné společ	3		
Myšlenky, psychologie	3		
Návštěvy lékaře, prohlídky, o	5	226,2	54,0
Péče o zdraví, prevence	6	151,0	23,5
Změna zdravotního stavu paci	9	180,3	42,6
Pomůcky	10	123,6	20,3
Motivování ostatních členů sk	14	208,8	30,7
Zábava	17	260,4	26,4

DLE JEDNOTLIVÝCH AKTIVIT
(ADLs)

Průměr reakcí

Průměr komentářů

Pomůcky	10	123,6	20,3
Péče o zdraví, prevence	6	151,0	23,5
Změna zdravotního stavu paci	9	180,3	42,6
Motivování ostatních členů sk	14	208,8	30,7
Návštěvy lékaře, prohlídky, o	5	226,2	54,0
Zábava	17	260,4	26,4

DLE JEDNOTLIVÝCH AKTIVIT (ADLs)		Průměr reakcí	Průměr komentářů
Pomůcky	10	123,6	20,3
Péče o zdraví, prevence	6	151,0	23,5
Zábava	17	260,4	26,4
Motivování ostatních členů sk	14	208,8	30,7
Změna zdravotního stavu paci	9	180,3	42,6
Návštěvy lékaře, prohlídky, o	5	226,2	54,0

DLE JEDNOTLIVÝCH AKTIVIT (ADLs)	Počet příspěvků	Průměr reakcí	Průměr komentářů
Zábava	17	260,4	26,4
Návštěvy lékaře, prohlídky, o	5	226,2	54,0
Motivování ostatních členů sk	14	208,8	30,7
Změna zdravotního stavu paci	9	180,3	42,6
Péče o zdraví, prevence	6	151,0	23,5
Pomůcky	10	123,6	20,3

DLE JEDNOTLIVÝCH AKTIVIT (ADLs)		Průměr reakcí	Průměr komentářů
Pomůcky	10	123,6	20,3
Péče o zdraví, prevence	6	151,0	23,5
Zábava	17	260,4	26,4
Motivování ostatních členů sk	14	208,8	30,7
Změna zdravotního stavu paci	9	180,3	42,6
Návštěvy lékaře, prohlídky, o	5	226,2	54,0

Počet komentářů**DLE TYPU****DLE DRUHU
OBSAHU**

23

Počet pouze textových
příspěvků 25

Počet výpovědí

37

Počet příspěvků "text a
multimédia" 60

Počet dotazů

44

Počet příspěvků s odkazem 2

Počet kombinací
(výpověď + dotaz)

30

Počet příspěvků "pouze
multimédia" 3

Počet doporučení

71

90

Počet "motivace a
pobavení"

22

24

75

DLE RÁMCE ADLs**DLE
JEDNOTLIVÝCH
AKTIVIT (ADLs)**

16

Základní denní aktivity 8

Koupání a sprchování

77

Instrumentální denní
aktivity 23

Osobní hygiena

2

Ostatní instrumentální
denní aktivity 17

Oblékání

11

Specifické aktivity 43

Toaleta

44

Pohyb a přemísťování
(v domácnosti)

41

STATISTIKY PŘÍSPĚVKŮ

3

Celkový počet příspěvků 90

41

Celkový počet reakcí 15929

33

Celkový počet komentářů 2451

11

Průměrný počet reakcí 176,99

17

Průměrný počet komentářů 27,23

38

119

17

59

38

43

71

32

35

64

Stravování

Komunikace a
interakce (z očí do
očí)

Uklízení a udržování
domácnosti

Hospodaření s penězi

Přemísťování (mimo
domácnost)

Vaření, příprava jídel

Nakupování

Užívání léků

Využívání
komunikačních
prostředků

Zábava

Sport a podobné
fyzické aktivity

Výběr pečovatелů a
zdravotnických
zařízení

Příznaky

Bezpečnostní
opatření

71	Nespavost a poruchy nočního chování
36	Svátky, narozeniny, výročí
9	Péče o zdraví, prevence
11	Sociální skupiny a jiné společenské akce
19	Stárnutí a umírání
66	Vyhledání pomoci (v rodině i mimo)
18	Návštěvy lékaře, prohlídky, operace
<hr/>	
0	
11	Kvalita zdravotnických služeb
1	Změna zdravotního stavu pacienta
12	Negativní pocity pečovatele (vina, vyčerpání, ztráta motivace)
1	Strach z budoucnosti
0	Pozitivní události
31	Finanční problémy
0	Vděčnost za existenci skupiny a poskytnuté rady, podporu
5	Motivování ostatních členů skupiny
2	Pomůcky
2	Myšlenky, psychologie

6

34

1

27

41

0

31

19

111

102

6

29

29

7

32

9

13

30

22

9

1

7

6

15

9

0

44

32

7

13

50

6

76

10

23

15

6

18

8

46

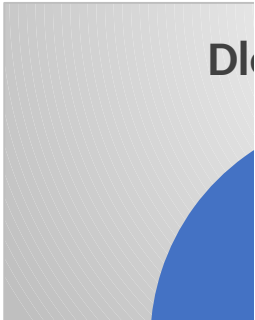
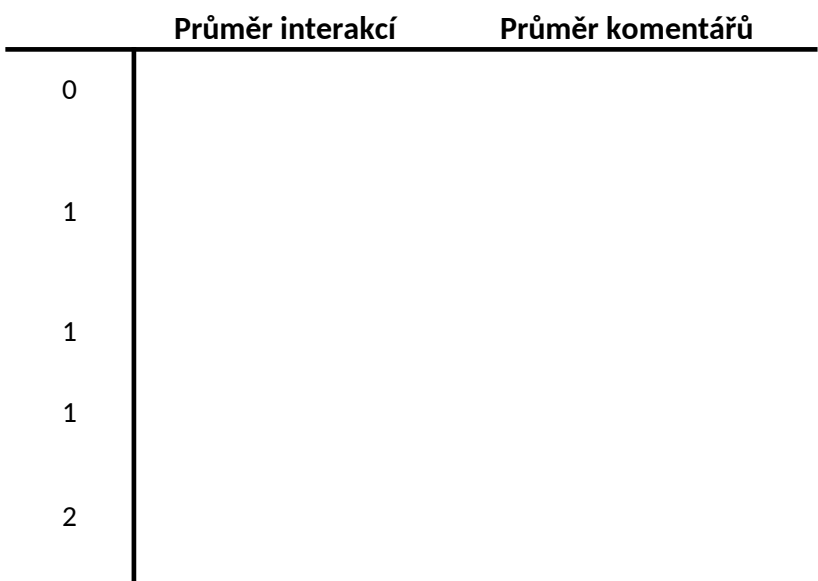
6

6

1



Průměrný počet reakcí 176,99
Průměrný počet komentářů 27,23

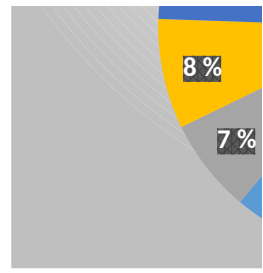


3
0

1
0
2
0
0
3
0
17
0

260,35	26,41
--------	-------

2
0
0



- Mot
- Zm
- Náv
- Sociální s
- Vděčnost za existenci skup
- Výběr pečov
- Pohyb

Prům

Návštěvy lékaře, pro
Motivování ostatních
Změna zdravotního
Péče o zc

Průměr

Návštěvy lékař
prohlídky, opera

0		
0		
6	151,00	23,50
3		
1		
0		
5	226,20	54,00

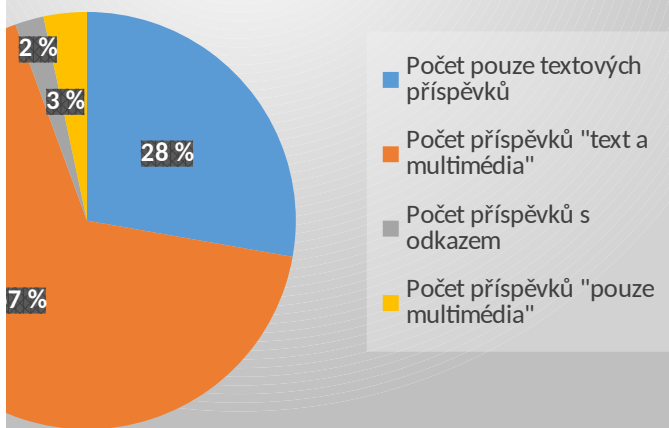
1		
9	180,33	42,56
0		
0		
2		
0		
2		
14	208,79	30,71
10	123,60	20,30
3		

Změna zdravotního sta-
pacienta
Motivování ostatní
členů skupiny
Zába
Péče o zdraví, preven
Pomůc

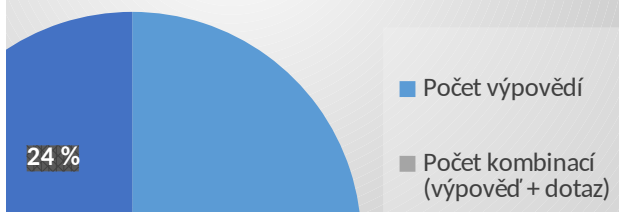
Poměr

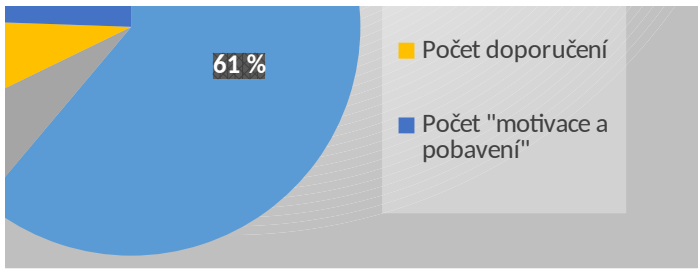
Návštěvy lékaře, pro
Motivování ostatních
Změna zdravotního
Péče o zc

Dle typu (pacient)

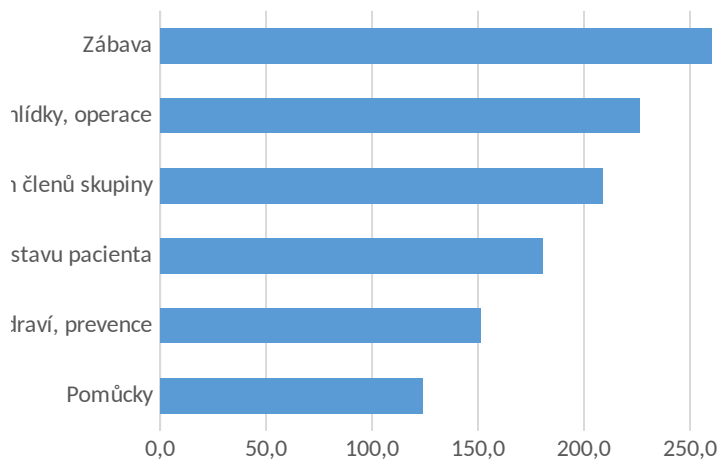


Dle druhu obsahu (pacient)



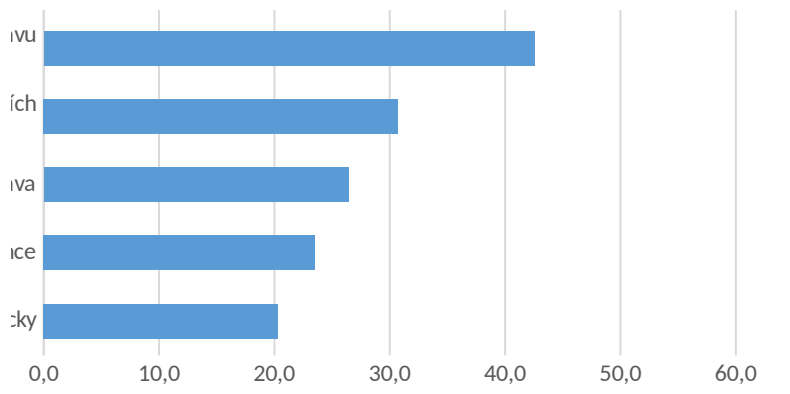


ěrný počet reakcí u jednotlivých kategoriích ADLs

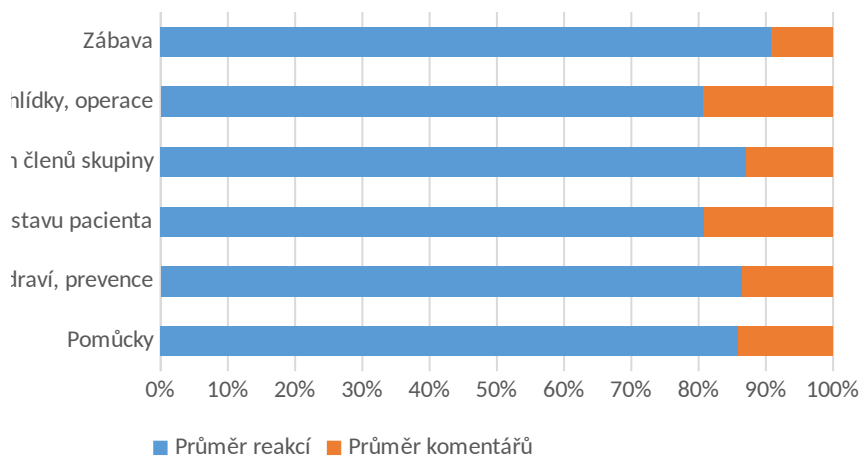


ěrný počet komentářů u jednotlivých kategoriích ADLs





reakcí a komentářů u jednotlivých kategorií ADLs
- Pacient



	Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Pečovatel 1	Text	Výpověď	Stárnutí a umírání	194
	Text	Výpověď	Změna zdravotního stavu pacienta	166
	Text	Výpověď	Změna zdravotního stavu pacienta	106
	Text	Dotaz	Vyhledání pomoci	0
	Text	Dotaz	Pomůcky	14
	Text	Dotaz	Péče o zdraví, prevence	10
	Text	Dotaz	Změna zdravotního stavu pacienta	5
	Text	Motivace a pobavení	Zábava	126
	Text	Výpověď	Výběr pečovatелů a zdravotnických zařízení	60
	Text	Výpověď	Pozitivní události	161
Pečovatel 2	Text	Kombinace	Vyhledání pomoci	0
	Text	Dotaz	Užívání léků	0
	Text	Dotaz	Pomůcky	1
	Text	Kombinace	Změna zdravotního stavu pacienta	8

Text	Kombinace	Stravování	8
Text	Dotaz	Výběr pečovatelů a zdravotnických zařízení	3
Text	Kombinace	Výběr pečovatelů a zdravotnických zařízení	7
Text	Dotaz	Kvalita zdravotnických služeb	7
Text	Dotaz	Pomůcky	3
Text	Dotaz	Vyhledání pomoci	5
Text	Kombinace	Negativní pocity pečovatele	19
Text	Kombinace	Nespavost a poruchy nočního chování	0
Text	Kombinace	Nespavost a poruchy nočního chování	20
Text	Dotaz	Péče o zdraví, prevence	4
Text	Dotaz	Vyhledání pomoci	5

Pečovatel 3			241	
	Text	Výpověď	Vděčnost za existenci skupiny a poskytnuté rady, podporu	84
	Text	Výpověď	Předání osobních informací	118
	Text	Výpověď	Příznaky	576
	Text a multimédia	Výpověď	Stárnutí a umírání	185
	Text	Kombinace	Péče o zdraví, prevence	

	Text	Výpověď	Změna zdravotního stavu pacienta	133
	Text	Kombinace	Výběr pečovatelů a zdravotnických zařízení	19
	Text	Výpověď	Zábava	18
	Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	112
	Text	Výpověď	Změna zdravotního stavu pacienta	41
	Text	Výpověď	Stravování	61
	Text	Dotaz	Stravování	3
	Text	Výpověď	Změna zdravotního stavu pacienta	40
	Text	Dotaz	Změna zdravotního stavu pacienta	19
				2
	Text a odkaz	Doporučení	Pomůcky	

Pečovatel 4	Text a multimédia	Dotaz	Pomůcky	3
	Text	Kombinace	Pomůcky	2
	Text	Výpověď	Strach z budoucnosti	675
				7
	Text	Kombinace	Užívání léků	
				40
	Text a multimédia	Dotaz	Pomůcky	
	Text a multimédia	Výpověď	Myšlenky, psychologie	524
	Text	Kombinace	Pomůcky	10

Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	882
Text	Dotaz	Vyhledání pomoci	1
Pouze multimédia	Doporučení	Příznaky	47
Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	209
Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	58
Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	176
Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	242

Pečovatel 5	Text	Dotaz	Bezpečnostní opatření	1
	Text	Dotaz	Vyhledání pomoci	4
	Text	Kombinace	Péče o zdraví, prevence	0
	Text	Dotaz	Bezpečnostní opatření	0
	Text	Kombinace	Změna zdravotního stavu pacienta	0
	Text	Dotaz	Změna zdravotního stavu pacienta	1
	Text	Dotaz	Péče o zdraví, prevence	20
	Text	Dotaz	Pomůcky	7
	Text a multimédia	Dotaz	Pomůcky	2
	Text	Dotaz	Změna zdravotního stavu pacienta	0
	Text	Dotaz	Užívání léků	4
	Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	2
	Text	Výpověď	Negativní pocity pečovatele	57
	Text	Výpověď	Myšlenky, psychologie	181

	Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	53
	Text	Dotaz	Pomůcky	4
	Text	Dotaz	Kvalita zdravotnických služeb	6
	Text	Kombinace	Předání osobních informací	2
Pečovatel 6	Text	Kombinace	Pomůcky	20
	Text	Výpověď	Stravování	115
	Text	Dotaz	Stravování	16
	Text	Kombinace	Příznaky	12
	Text	Kombinace	Příznaky	18
	Text	Kombinace	Pomůcky	8
	Text	Kombinace	Pomůcky	13
	Text	Dotaz	Pomůcky	11
	Text	Kombinace	Pomůcky	5
	Text	Kombinace	Péče o zdraví, prevence	16
	Text	Kombinace	Změna zdravotního stavu pacienta	10
	Text	Kombinace	Stravování	5
	Text	Dotaz	Pomůcky	8
	Text	Kombinace	Pohyb a přemísťování (v domácnosti)	14
	Text	Kombinace	Pohyb a přemísťování (v domácnosti)	7
	Text	Výpověď	Pohyb a přemísťování (v domácnosti)	1
	Text	Dotaz	Nespavost a poruchy nočního chování	6
	Text	Kombinace	Pomůcky	2
	Text	Kombinace	Péče o zdraví, prevence	2
	Text	Výpověď	Pomůcky	31
	Text	Kombinace	Přemísťování (mimo domácnost)	1
	Text a multimédia	Dotaz	Přemísťování (mimo domácnost)	22

Text	Výpověď	Změna zdravotního stavu pacienta	3
Text	Kombinace	Výběr pečovatелů a zdravotnických zařízení	6
Text	Kombinace	Přemísťování (mimo domácnost)	6
Text	Kombinace	Koupání a sprchování	6
Text	Dotaz	Návštěvy lékaře, prohlídky, operace	3
Text	Kombinace	Pohyb a přemísťování (v domácnosti)	26
Text	Dotaz	Užívání léků	0
Text	Dotaz	Nespavost a poruchy nočního chování	1
Text	Kombinace	Návštěvy lékaře, prohlídky, operace	12

Aktivita	Počet příspěvků
Osobní hygiena	0
Oblékání	0
Toaleta	0
Komunikace a interakce	0
Uklízení a udržování do	0
Hospodaření s penězi	0
Vaření, příprava jídel	0
Nakupování	0
Využívání komunikačníc	0
Sport a podobné fyzické	0
Svátky, narozeniny, výro	0
Sociální skupiny a jiné	0
Finanční problémy	0
Koupání a sprchování	1
Strach z budoucnosti	1
Pozitivní události	1
Vděčnost za existenci s	1
Zábava	2
Bezpečnostní opatření	2
Stárnutí a umírání	2
Návštěvy lékaře, prohlí	2

Kvalita zdravotnických s	2
Negativní pocity pečova	2
Myšlenky, psychologie	2
Předání osobních infor	2
Přemísťování (mimo do	3
Pohyb a přemísťování (4
Užívání léků	4
Příznaky	4
Nespavost a poruchy nc	4
Výběr pečovatelů a zdr	5
Stravování	6
Vyhledání pomoci (v ro	6
Péče o zdraví, prevence	7
Motivování ostatních čl	7
Změna zdravotního stav	14
Pomůcky	19

DLE JEDNOTLIVÝCH AKTIVIT (ADLs)		Průměr reakcí	Průměr komentářů
Vyhledání pomoci (v ro	6	2,5	11,5
Užívání léků	4	2,8	30,5
Nespavost a poruchy nc	4	6,8	24,5
Pomůcky	19	9,8	31,6
Pohyb a přemísťování (4	12,0	44,0
Výběr pečovatelů a zdr	5	19,0	44,4
Péče o zdraví, prevence	7	33,9	37,6
Stravování	6	34,7	40,5
Změna zdravotního stav	14	46,0	21,7
Příznaky	4	48,8	21,3
Motivování ostatních čl	7	231,7	16,0

DLE JEDNOTLIVÝCH AKTIVIT (ADLs)		Průměr reakcí	Průměr komentářů
Vyhledání pomoci (v ro	6	2,5	11,5
Motivování ostatních čl	7	231,7	16,0
Příznaky	4	48,8	21,3
Změna zdravotního stav	14	46,0	21,7
Nespavost a poruchy nc	4	6,8	24,5
Užívání léků	4	2,8	30,5
Pomůcky	19	9,8	31,6
Péče o zdraví, prevence	7	33,9	37,6
Stravování	6	34,7	40,5
Pohyb a přemísťování (4	12,0	44,0
Výběr pečovatelů a zdr	5	19,0	44,4

Kategorie ADLs	Počet příspěvků	Průměr reakcí	Průměr komentářů
Motivování ostatních čl	7	231,7	16,0
Příznaky	4	48,8	21,3
Změna zdravotního stav	14	46,0	21,7
Stravování	6	34,7	40,5

Péče o zdraví, prevence	7	33,9	37,6
Výběr pečovatelů a zdravotníků	5	19,0	44,4
Pohyb a přemísťování (včetně zvedání)	4	12,0	44,0
Pomůcky	19	9,8	31,6
Nespavost a poruchy nespavosti	4	6,8	24,5
Užívání léků	4	2,8	30,5
Vyhledání pomoci (včetně vyhledání lékaře)	6	2,5	11,5

Počet komentářů**DLE TYPU****DLE DRUHU OBSAHU**

61

Počet pouze textových příspěvků	87
---------------------------------	----

Počet výpovědí	23
----------------	----

42

Počet příspěvků "text a multimédia"	9
-------------------------------------	---

Počet dotazů	36
--------------	----

33

Počet příspěvků s odkazem	1
---------------------------	---

Počet kombinací (výpověď + dotaz)	34
-----------------------------------	----

5

Počet příspěvků "pouze multimédia"	6
------------------------------------	---

Počet doporučení	2
------------------	---

43

Počet "motivace a pobavení"	8
-----------------------------	---

53

23

30

DLE RÁMCE ADLs**DLE JEDNOTLIVÝCH AKTIVIT (ADLs)**

52

Základní denní aktivity	11
-------------------------	----

Koupání a sprchování	1
----------------------	---

26

Instrumentální denní aktivity	9
-------------------------------	---

Osobní hygiena	0
----------------	---

15

Ostatní instrumentální denní aktivity	32
---------------------------------------	----

Oblékání	0
----------	---

9

Specifické aktivity	51
---------------------	----

Toaleta	0
---------	---

0

Pohyb a přemísťování (v domácnosti)	4
-------------------------------------	---

34

STATISTIKY PŘÍSPĚVKŮ

Stravování	6
------------	---

62

Celkový počet příspěvků	103
-------------------------	-----

Komunikace a interakce (z očí do očí)	0
---------------------------------------	---

12

Celkový počet reakcí	6210
----------------------	------

71

Celkový počet komentářů	3305
-------------------------	------

Uklízení a udržování domácnosti	0
---------------------------------	---

20

Průměrný počet reakcí	60,29
-----------------------	-------

Hospodaření s penězi	0
----------------------	---

19

Průměrný počet komentářů	32,09
--------------------------	-------

Přemísťování (mimo domácnost)	3
-------------------------------	---

13

Vaření, příprava jídel	0
------------------------	---

27

Nakupování	0
------------	---

0

Užívání léků	4
--------------	---

70

Využívání komunikačních prostředků	0
------------------------------------	---

13

Zábava	2
--------	---

4

Sport a podobné fyzické aktivity	0
----------------------------------	---

33

24

Výběr pečovatelů a zdravotnických zařízení	5
--	---

9

Příznaky	4
----------	---

212

Bezpečnostní opatření	2
-----------------------	---

55

Nespavost a poruchy nočního chování	4
-------------------------------------	---

29

54

5

27

10

64

20

12

26

0

10

33

138

58

87

128

25

Svátky, narozeniny,
výročí 0

Péče o zdraví,
prevence 7

Sociální skupiny a jiné
společenské akce 0

Stárnutí a umírání 2

Vyhledání pomoci (v
rodině i mimo) 6

Návštěvy lékaře,
prohlídky, operace 2

Kvalita zdravotnických
služeb 2

Změna zdravotního
stavu pacienta 14

Negativní pocity
pečovatele (vína,
vyčerpání, ztráta
motivace) 2

Strach z budoucnosti 1

Pozitivní události 1

Finanční problémy 0

Vděčnost za existenci
skupiny a poskytnuté
rady, podporu 1

Motivování ostatních
členů skupiny 7

Pomůcky 19

Myšlenky,
psychologie 2

91

Předání osobních
informací

2

5

14

6

1

4

10

10

27

10

19

9

10

77

60

7

2

24

0

24

34

0

31

10

12

15

34

48

39

23

45

46

21

8

40

19

15

43

79

48

3

23

16

15

91

13

54

28

33

5

51

19

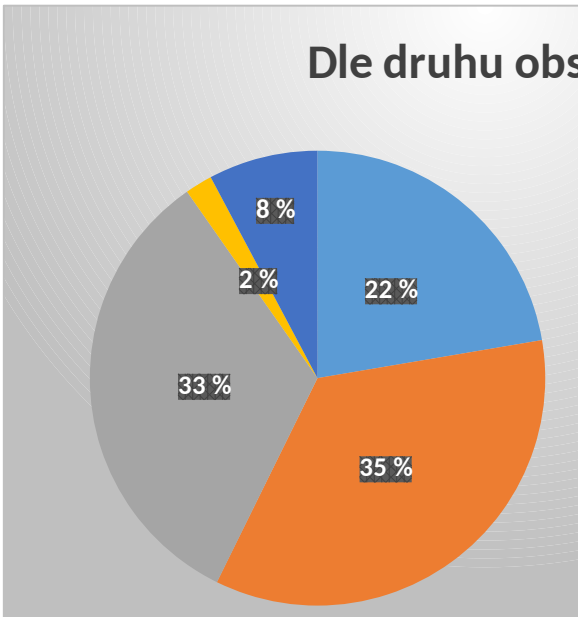
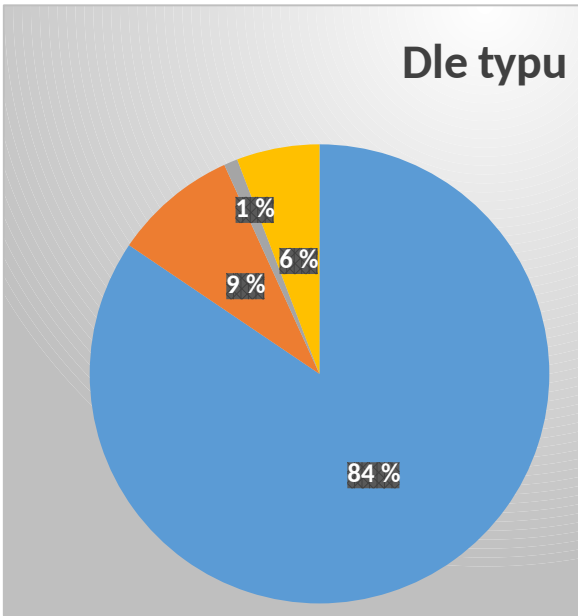
46

31

5

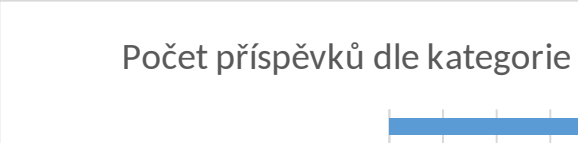
56

Průměrný počet reakcí	60,29
Průměrný počet komentářů	32,09

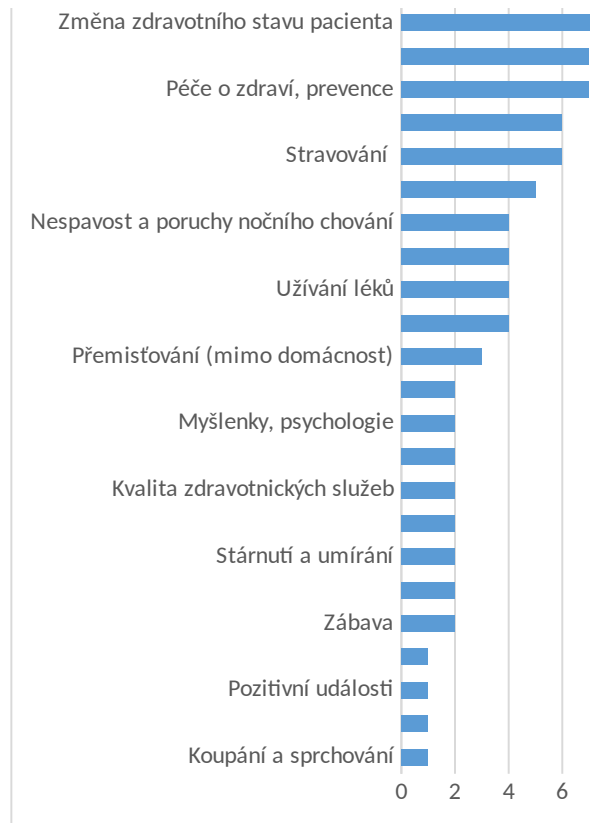


Průměr reakcí **Průměr komentářů**

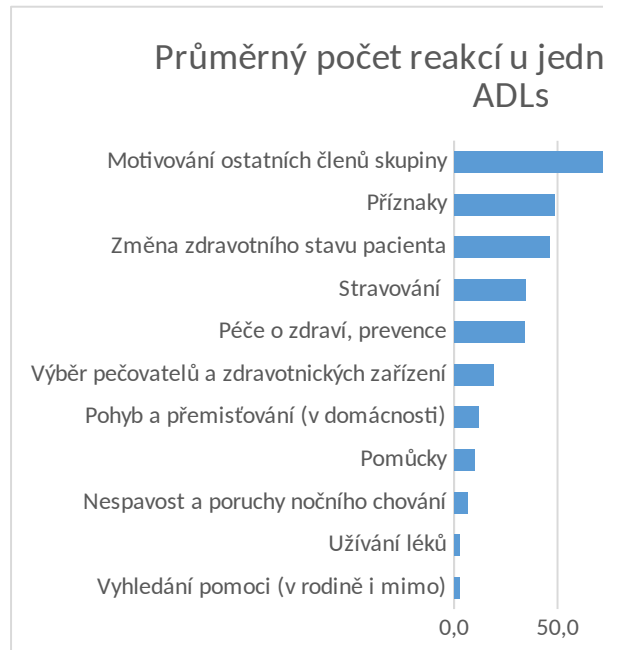
12,00	44,00
34,67	40,50



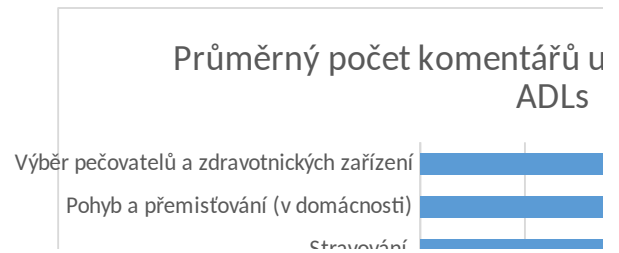
2,75	30,50
------	-------



19,00	44,40
48,75	21,25



6,75	24,50
------	-------

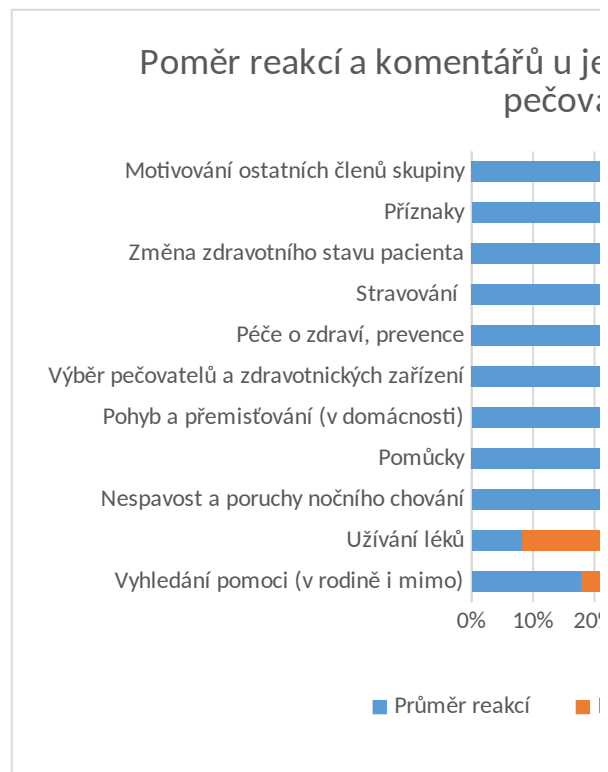


33,86	37,57
-------	-------

2,50	11,50
------	-------

46,00	21,71
-------	-------

231,71	16,00
9,79	31,58



- Počet pouze textových příspěvků
- Počet příspěvků "text a multimedia"
- Počet příspěvků s odkazem
- Počet příspěvků "pouze multimedia"

sahu

- Počet výpovědí
- Počet dotazů
- Počet kombinací (výpověď + dotaz)
- Počet doporučení
- Počet "motivace a pobavení"

ADLs (pečovatel)

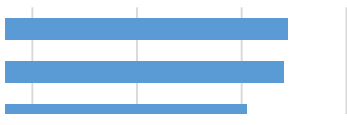


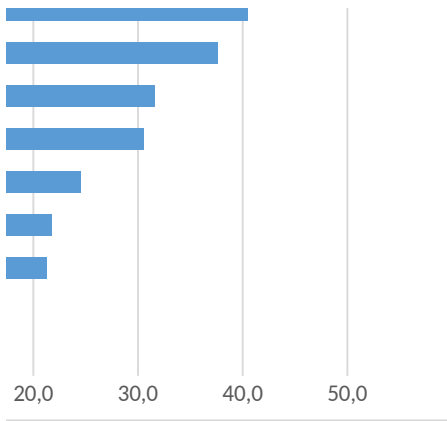


otlivých kategorií

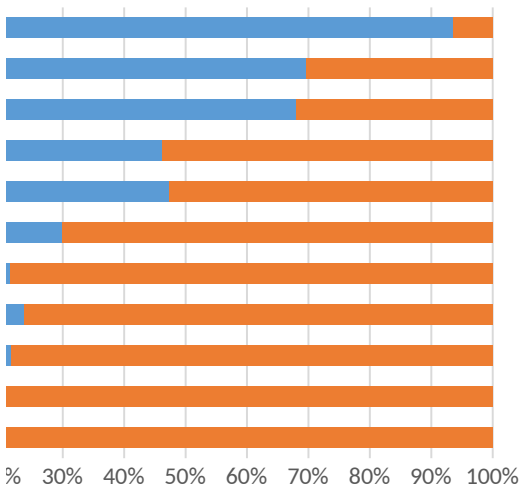


jednotlivých kategorií





ednotlivých kategorií ADLs -
atel



Průměr komentářů

Pacient 1

Počet příspěvků: Žena
36
Přispívá: Pacient
Příspěvky:

1. (7. březen 2022) Good morning! Don't forget to smile and laugh. Enjoy your day today the weather is starting to pick up. Spring is near! Remember to love your family and hold them tight. Thank God for all of your blessings and put down your cell phone to hear what you might be missing. #rockinals #tamuraisadventure + *fotografie*

2a. (3. březen 2022) I have seven more days before my surgery. This surgery is life-threatening due to my weakness. Either way I am prepared and hoping I wake up with a smile and see my family in front of me. However I look forward to the moment that I see Jesus and no longer hurt. Things I would leave with all of you is never give up hope. Put God first pray to him, tithe, thank him for all the blessings. Second your family hold them close, capture all the memories even if it's photos better that most silly and unattractive. Those are the ones that create the most memories. Make videos, back up those backups and revisit them often. Whatever happens on Thursday is meant to be. I am okay with this I am sad how my family may feel whether I am gone or the difficulty they have agreed to to fight to keep me alive. It takes a village. Always ask for help. Never be too proud. Always smile and laugh it just makes you feel better.

2b. If I don't wake up here on earth I pray that my legacy continues and all the hard work has not been swept on the the rug. That people remember I wasn't doing it just for me I was doing it for everyone in my situation or similar situation. I pray that they continue making ripples and spreading awareness.

When I do wake up it's going to be quiet for a little while. I haven't done a very good job practicing my eye gaze. My tick tock account has exploded and I get about 500 comments an hour. It's amazing when you ask your husband to be the voice 🗣️ for those who have my phone number thank you for always checking on me. Something I'm not used to because I've always been the person to check on you. Thank you for always being there and my support and please don't stop. It's easier for me to answer it the phone or text than me trying to thumb in a phone number and hit send. As far as how I'm feeling I still feel very weak and then lots of discomfort but that's to be expected. ALS is not an easy disease. I haven't been out of my bed for about 2 months except for a couple of hospital visits. I am on the phone 6 hours a day with doctors and lawyers trying to organize my care.

So the countdown begins! Either way I feel like I'm in a win-win situation. More time with my family to create more memories and chaos or more time with God.

#rockinALS + video a 2 fotografie

3. (27. únor 2022) Attended church with these guys and the guy behind the camera 📷 taking a very little low key day. So weak every time I am moved. Thank you for all the encouragement, snow angels, and sharing your adventures They have brought such a huge smile to my face! David would say sometimes even tears of joy with the hash mark on the wall before how many times I cried.

Don't forget to laugh and smile. Thank God for another day.

#rockinALS #tamuraisadventure + fotografie

4. (23. únor 2022) So many numbers in my mind

8593 days since I married my best friend

858 days since I was diagnosed with ALS

518 days since my last step

492 days since I accepted Jesus in my life

53 days since we saw our oldest boy

41 days since I lost an important part of my life, my father in law

40 days since we had a caregiver

39 days since we saw our youngest boy

16 more days until I get to breathe better

6 more days until I turn 46

My days are not done yet! I plan on adding so much to my life. Everything flies by so quickly but for me I live one day at a time.

Thank you God for every day 🙏🙏

#rockinALS #tamuraisadventure +7 fotografí

5a. (20. únor 2022) Yesterday it took until almost 2:00 p.m. and a shower when I realized was starting to feel better. I'm still not out of the woods but David has been doing so good about making sure I do not miss any fluids or medication.

I was planning on staying in bed all day yesterday but after the shower I was feeling somewhat normal. So David and I went to on a date to the movie theater. We caught the 3:00 and saw the movie uncharted. It was a wonderful adventure movie with Matt Damon and Tom Holland. After the movie was over David said would you like to do a second movie? I thought about it I assessed my situation and his. How we were feeling. We were like two little teenagers left in a movie theater. So we stayed for dinner, I took my medicine, hooked me up with more formula and water. We stayed in the lobby until 7:00 it was about an hour and a half. Then we went and watched the movie dog with Channing Tatum. What a wonderful movie highlighting such a hero.

5b. We didn't even go to bed until 10:00 last night and now we are up and getting ready to head to church. I Thank God for another day to create memories with my husband. We are going to fight this dehydration with a no questions asked kind of situation. We are going to fight his back pain and together we are going to be so strong. The laughter that has filled this house in the past 2 days has been so wonderful and relieving I don't know the rest of the day but I do know I am looking forward to church and thanking God for helping me get through all of these difficult moments.

We even started eye gaze training for David yesterday so that he knew how to operate it when I'm unable to help. I even trained him on how to use my Snapchat lol. Don't be surprised if you get silly videos from him 🤪 I hope everybody has a blessed day today, don't forget to laugh, smile and enjoy every moment you have with those that you love.
#rockinALS #tamuraisadventure +3 fotografie

6. (13. únor 2022) Oh how I've missed you guys! I'm sorry I have not been posting this often in this group. Here is an update on my past 2 months. Although my fitness pal maybe super excited about my weight I am not. If I was walking and healthy I would be jumping for joy. Don't worry this is a positive post but my weigh in was 164. Between the stress, anxiety, depression, not wanting to eat, and dehydration I have put myself in a dangerous situation. 20 lb in 2 months. Yes I am working with a medical professional. No I do not want to go to the hospital and do not plan on it unless this does not turn around over the weekend. Yes I am feeling better today! So much better that I am headed to church ♥ I am still fairly weak but I miss going to church. David and I are going to get out of this bedroom and out of this house and that my friends is the plan. We got this! God is good I'm not giving up at all no matter what!
#rockinALS #tamuraisadventure +3 fotografie a 1 video

7. (6. únor 2022) Even if David and I are at home in bed. I can see the sun shining through my window. Yes I have been down for about a week but sometimes taking care of those that take care of you is so important. I really wanted to make sure my husband takes some down time for himself and gets a little relief in his back. I don't know what it's like to be in his shoes but from my point of view I can tell that when you were responsible for the person that is unable to do anything for them themselves and you're not well it makes everything 10 times harder. I would rather lay beside him and hold his hand than want him being pain. Thank you God for the sun shining through my windows, for another day with my husband and for all the four-legged buddies in our bed.
#rockinALS +2 fotografie

8a. (4. únor 2022) So many people are sad when they read this. Please know I'm excited that I will be able to breathe. I am aware of the risks that are very high. If I survive the surgery I'll come out with a smile. If I do not then I will be in heaven watching over all of you knowing that my purpose was done here.

So why not come up with an extra plan. So far this month has been a blessing. On the first of February I get to meet my awesome surgeon. On the second of February David and I had a spa day. On the 3rd of February I got to spend time with my middle son and go to special visit from Merla Roy who spoiled us with cookies and some beautiful flowers. Today I get to spend the day with Grammy watching our favorite cooking show.

Now the next part I am going to talk about I know in the comments I will get disagreements. Please know that I do understand the other portion but I am very confident that my body will disagree. When I wake up with a smile from surgery I will no longer be able to communicate with my voice. This surgery is permanent, yes we could deflate the cuff just enough so that air could pass over my vocal cords but if I'm already having a difficult time talking and it uses so much energy why would I want to use more? The same goes with eating I already have a difficult time getting food caught. We could deflate the cuff so that I could eat but again it will use so much energy and I already have a hard time with this now so why risk it.

8b. This doesn't mean I'm giving up but I am trying to be very realistic. I am embracing the surgery with open arms and so grateful that I will be able to breathe better. Now for the list of food choices that I want to get out of the way. I still eat but in small quantities as I stated before food gets stuck. I still try to enjoy every bite. I figured why not have a few of my favorites before A favorite treat is the chocolate frozen yogurt at Sam's club. Definitely going to have to have some of that. I would say a whole lobster but I could never eat the whole thing and my husband is not a huge fan so why not lobster tail.

A very well cooked steak like melt in your mouth steak.

I would say nachos but I have so much nacho cheese here I think David has that part covered ☺ As far as any other food maybe one last trip to Tuscan bistro for their fried calamari the best ever. Now for my voice If I ever have the chance to talk to Steven Tyler, Keith Urban, to see my best friend Jessica one more time in person, just silly little things like that. Spending the last 30 days with my husband and talking his ear off. Wait I already do that lol. The list is huge and kind of out there but I think that just being able to talk about it would be wonderful. The final thing would be just know That David promised if I woke up and survived this thing we're not just going to stay home. We are getting out of the house It won't be easy but we're going to do it so the real bucket list is not changing. +2 *fotografie*

9. (3. únor 2022) Did you know that healthy adult lungs capacity is 6 liters? I am currently at 1.30 liters. Talking uses so much energy but I just want to keep talking. I'm grateful that I have been able to prolong the process until now. I will be almost 1.5 years since I had to decide if I wanted a tracheostomy or not. I struggled with how my family felt thinking I was being selfish. Last August I was able to share my fears with my family and learned that they are here for me no matter what. I can honestly say I needed to hear that from them.
So I am going to move forward with them right by my side. I am ready to move forward and look forward to breathing easy. I have been thinking of my new fashion and how I can make it look fabulous 😊
This will be my new favorite accessory. Bringing the choker and ascot style back. *+fotografie*

10. (1.únor 2022) Step one is now complete! Today they stuck a camera in my nose and down my throat to view the airways. the doctor said I had a beautiful airway perfect for my tracheostomy. All the paperwork has been signed and risks have been discussed.
Step two is to wait for the surgical team to call with a date We are scheduling approximately 3 -4 weeks out.
We're still looking for a caregiver we have interviewed and waiting for paperwork to return.
The process for the surgery I will be there Minimum 7 days but it could be at little longer due to My blood clot history and having to wean off of the medication for the surgery.
There will be a second surgery scheduled after this one for the port that will help provide nutrition and hydration.
Overall I get to add a new doctor to my collection and so far the sun has warmed the day up. Today has been a great day.
Don't forget to smile and laugh!
#tamuraisadventure +3 fotografie

11. (29. leden 2022) My son shared this with me this afternoon and it sure did get a chuckle out of me. I hope everyone is all bundled up safe and warm. We have some great drifts for some snow angels tomorrow!
If you don't have snow it's okay because any angel is accepted. I've seen sand angels and paper angels. We've even made angels out of packing peanuts on the floor.
Don't forget to smile and laugh today. Hold your loved ones close 🤗
I plan on doing mine tomorrow hopefully. I may not be able to move but my husband can help me with my hooyer It will be a little painful but it'll be well worth the laughter and smiles.
#snowangelsfortammy #rockinALS +video

12. (27. leden 2022) From Georgia to Maine this weekend We are going to get what they call " the bomb ". This means snow for everyone! I can't wait to see all the snow angels. Don't forget to tag me ☺ use #snowangelsfortammy ❤️
Don't forget to smile and laugh today!
#rockinALS #tamuraisadventure +2 *fotografie*

13. (22. leden 2022) Today I had my pulmonary function test. I may have not done the greatest but I can say that I had a very successful day with my sister-in-law. One day at a time it's all we can do and enjoy every second of every moment in that day. Today we had great memories and we were able to look back on some good old ones as well. I hope every one of you had a wonderful memorable day as well .
Just don't forget to laugh, smile and thank God for every day you have with your family.
#tamuraisadventure #rockinALS +fotografie

14. (18. leden 2022) I am so thankful for northern light home care, my nurse Leah, and coastal med tech Kate and Elizabeth. They have been so supportive during this whole crazy month of trying to prepare for a surgery that will be delayed. Please continue to pray that my pulmonary function test is absolutely amazing on Friday. That way we can delay the surgery even more.
I have low SPO2 and a high blood pressure. Completely understandable right. But I'm still smiling! Below is Parker and Dan my boys yesterday just before I had to say goodbye to Parker. I'm just missing my oldest Tyler who is traveling right now for work. I love them so much, these crazy boys have been so helpful and learning as much as they can about my disease. Off to watch my movie with Debbie and cuddle with Emma and the cats. Thank you for keeping my family in your prayers.
Thank you to the American Red Cross for getting our marine home quickly. I wish I didn't have to return him though!
#rockinALS #tamuraisadventure +fotografie

15. (10. leden 2022) It's stretch time!

If you're reading this then take a moment to stretch. Self-care is so important and just a little stretch feels so good. It helps get your blood flow moving and wakes you up. Take your arm and put it behind your neck actually it would be your hand behind your neck then take your other hand put it behind your head and grab your elbow. Gently pull not so that it hurts really bad but just enough to feel the stretch. Now hold Do both sides. Now shake it off. Then rotate your head counterclockwise slowly. Do this five times each direction. Don't have time you do I promise it's only if you minutes and you could do it at work. Now pick up one leg while you're standing and pull your foot towards the front of you feel the stretch be careful you might lose your balance. Do both sides remember just stretch no pain. Now slowly try and touch those toes and back up only holding just a little while. Today I thought about the importance of stretch time even for those of us that are unable to move just gentle stretching to help move stiff bones and muscles. Today I have decided to start calling stretch time again but this time for my caregivers because it's so important to get that blood flowing. I used to do it at my old job's and everyone would start moaning and groaning but then laughing. So if you see my clock just take a second and stretch out or stretch your person out that's laying in bed or sitting in the chair. Let's get that blood flowing I hope you have a fantastic day today! #rockinALS #tamuraisadventure +fotografie

16. (9. leden 2022) Just out of reach.

this is me two years ago standing with a walker and of course walking slowly.

Today I depend on others to help me move. Placing the straw in my mouth, putting in the remote to my bed or my chair in a particular position. Having my cell phone just right or even the blanket in a special way..

The slightest distance would make me unable to use anything and sit and wait. The best way to describe it would be unable to reach something high in a cupboard. Or even being a little kid and having somebody hold something they wanted really really high in the air. Just enough out of reach so you wouldn't be able to use it without help.

I never thought that just a millimeter would make a huge difference.

So today's lesson is adjustment as necessary always ask for help even if it's just for a millimeter.

#tamuraisadventure #rockinALS +2 fotografie

17. (6. leden 2022) My husband came up with this idea We found the cart at a store here in Maine that's pretty popular. But I did find one online at Michaels how convenient. This holds my vent, my suction, my modem for my vent, the humidifier and the cough assist. He used a shower curtain rod on the side zip ties to hold everything. And special hooks that are holding the tubes in masks we use electrical tape. He also used a surge protector on the side of the cart that when plugged in will charge all components. This is been very useful with traveling.

I know a lot of you have been asking how to organize and I wanted to share.

For medical supplies he bought two shoe holders that hang on the back of the door and we have labeled them for easy access for my home nurses when they come. Those he bought at Target typically \$10 each but when you go to the CVS pharmacy here they give you a \$5 coupon every time with your prescriptions so in total we spend \$10. Below are the photos.

The best thing about all of this is everything is hidden so if you were to walk into my home you would feel at home instead of feeling like you're in a hospital. #rockinALS #tamuraisadventure +4 fotografie a odkaz

18. (1. leden 2022) I started a list of changes on January 1st 2021. Today I decided that my list should be much different as the changes looked scary. I decided to list what I am grateful for instead of the negative. I'm alive. I survived challenges of health risks. I have my family. My wheelchair has been upgraded I'm healthy. Went to my first concert in a wheelchair to see Brad Paisley. I can feel touch. I have a wonderful washer and dryer. We spent the summer traveling to 54 locations thanks to an awesome couple from Dirigo treasure hunt in Maine. I got to see our Marine in north Carolina. I have three wonderful caregivers. Met the singer songwriter of my song, 'Willow Tree' Mary Desmond. Went to an ALS concert starring Brandon Parsons and Jeff Neal also known as the drunken fiddler, as well as Ms Mary. Got my Covid vaccine fully and boosted. Watched Parker graduate boot camp. Was admitted to the hospital for a heart attack called broken heart syndrome and lived. I have witnessed God's blessings in person. The list is so much longer but look at the moments ☺

Thank you for a wonderful year ☺

Don't waste thinking about what you lost but what you gained.

#rockinALS #tamuraisadventure +2 fotografie

19. (17. prosinec 2021) Can you frog my legs?

Can you straighten my legs?

Can you put my braces on?

Can I push the button on my chair?

Can you turn my chair on?

I just ran out of water

I think my catheter is pinched

Alexa "did you just take your medicine?"

And repeat at least 20 times in the day

Help my arm is falling.

Can you please pick up my left arm and move it onto my stomach.

Can you please help me with my phone!

And repeat almost every hour on the hour at night when we should be sleeping.

Grateful for April today I've kept her pretty busy We have now successfully tried every piece of Tammy furniture today, Even the toilet... I think I just wanted to try the toilet just cuz.

#rockinALS +2 fotografie

20. (11. prosinec 2021) What's happening?

The generator will be installed just before Christmas by Lowe's Home Improvement .

The propane lines will be installed and attached to the house by David Pike contractor shortly after.

Then about a week after that the propane tanks four of them will be delivered by Fabian Oil .

Next week we will be having a video meeting with Northern lights head manager, coastal med tech, my attorney, my advocate, David and April. To discuss risks, surgery dates, training dates and more.

Things have been a little rough around my edges but with a little guidance I know that we got this. David has done so much to make sure everything goes just right. ♥

#rockinALS #tamuraisadventure #mylove +2 fotografie

21. (29. listopad 2022) By the year 2022 I will no longer be able to speak with the voice I was born with. Not due to surgery, due to progression. I will have a machine breathing for me. I will have people driving my wheelchair for me. I feed through a hole in my stomach with a machine. Sometimes my husband hand feeds me too!
My home will be equipped with everything I need to be as comfortable as possible. My high risk status will need to be taken seriously. No more random visitors.
Eyes on me 24 hours a day. Security cameras needed.
I feel like I am a human rag doll with pretty nails and healthy hair.
I will have no control of what I do except for what I say.
In 2022 I will be transformed into a bionic woman. Are you ready? I am!
It's not easy. I do cry, I hurt, I whine but I know I got this.
The great things for 2021 I will share soon as I have a running list.
Just know no matter what trust in the name of Jesus ♥ I got this! My mind and soul will stay strong.
#rockinALS #tamuraisadventure +2 fotografie

22. (26. listopad 2022) Generator scheduled for install ✓ Thank you David for making sure we will have a full powered warm house even if there is no power.
Adventure Van is still in the shop but will be picked up tomorrow!
Sheepskin arrived from an anonymous kind soul 🐏 I cannot wait to try it out tonight.
Catheter has been changed. Unfortunately not a great experience but I'm still smiling and I'll be okay after maybe a shot of whiskey.
David is home early and will be off for the next two days. I get to spend the day with Merla tomorrow while David does a man date with his friend. I cannot wait!
Now to pick up the recliner but probably not today. But very soon.
David definitely has me be on Christmas this year! Not quite sure how I'm going to match this one.
#rockinALS +4 fotografie

23. (19. listopad 2022) What is the best thing about your journey with ALS?

The best thing about my journey, this is kind of a strange question. Some would say that ALS is not a preferred journey. I say maybe I have it so I can help others become more aware. There is always a purpose for everything. Right?

Yeah I kinda got the pooppy end of the stick. Honestly though ALS has given me a new reason to fight. There are days I want to completely give up and that is ok. (Usually no one sees those days unless you are my husband.)

Other days I am all about a challenge. (This is a BIG challenge)

The best thing about this Journey is the love and support I get from all of you. However my husband David gets the BIGGEST kudos. Without him I am not sure how this journey would be. He is definitely my rock.

The best moment of my ALS journey , Feb 28, 2020 (I can change the question if I want to) would be snorkeling with my husband and Aunt Holly at Discovery Cove. Actually I was not swimming. I was floating, and I am sure if my face was not wet you would see the tears of joy. It was the best experience I have ever had in my entire life. I felt normal and would have stayed there forever 🤔

#alsawarenesschallenge #rockinALS +fotografie

24. (13. listopad 2021) How did ALS clinic go?

Well to be honest I had typed it huge post before this and I took too long to type it that Facebookq refreshed. 🤔

So here is the quick version. We are decreasing the baclofen as I am a limp noodle. The team is in favor of the tracheostomy as I dropped from 56% to 37% lung function in two months. My right hand is squeezing 5 pounds now and the left we did not test as it is at 0.

My chair control will be done by my people from the back of my chair and eventually I will have a program to operate everything with my eyes.

So much preparation in so little time.

#rockinals +fotografie

25. (5. listopad 2021) Tracheostomy supplies are now on order. I just got my phone call from respiratory. They are planning to gather all materials and supplies before surgery. It's getting real! Elizabeth has 25 years of invasive ventilation and Kate is the bomb diggity! They are also going to get refresher training which makes me even happier.

Friendly reminders were

I cannot be alone. Reliable care with an open mind is necessary.

After surgery I will no longer be able to talk but great news is I have an amazing way to communicate and you'll still hear my voice.

My care will need to be done by the book no shortcuts.

Got to find a generator that will run the house with all the vital machines that I have to use.

Thank you Coastal med tech, Brenda and Doctor Noack 🙏

#rockinALS #tamuraisadventure +3 *fotografie*

26. (22. říjen 2021) All my life minus my goat rash 3 years ago. I have had perfect skin on my face. I never washed my face with soap, just warm water and a little hair conditioner to remove my eye makeup. Never oily and never dry. I know some would think you should use soap but if I did I would break out in all pimples so water was the best medicine for my skin.

Malnutrition and dehydration is dangerous for sure, (not being fully honest on what I could or couldn't do) and it was not good to my skin or hair.

My feeding pump is my best friend and always hooked up to me! 🙏

This is so frustrating, if you see me close you can visually see all of the crusties. All over my face. My face feels like a mud mask is still on it and it's cracking. I could care less about wrinkles, I love wrinkles, I believe wrinkles are a sign of wisdom and happiness. I don't need a filter to hide everything. I do however need to find something that is not going to make it worse. Why it is so important when you have ALS to tell others the difficulties that you are having. Even if it is the hardest thing. Eating and drinking are so hard for me to do, I just took too long to tell somebody.

#rockinALS #tamuraisadventure +5 *fotografii*

27. (10. říjen 2021) Last night I hit a hard turn around 7pm. My body, my speech, chewing and swallowing. We woke up at 9 this morning and watched church with our four legged friends.

I feel weak, everything that touches my skin causes pain. However this guy has figured out a way to make sure we are warm and he doesn't hurt. 🙏

Meet my grandson Leo 🙏

Planning on a local adventure with David. Movies and dinner.

#tamuraisadventure #rockinALS +5 *fotografii*

28. (8. říjen 2021) Little did I know that this accomplishment will be one of many. Little did I know that in 12 Days from this accomplishment I would get knocked down so hard.

Look at me now! You can knock me down but I WILL continue to push forward.

In 12 Days I will be celebrating my 2nd ALS Birthday with God and my family by my side.

My adventures will never stop.

#tamuraisadventure #rockinALS +fotografie

29. (1. říjen 2021) do you consider ALS a blessing or a curse to know the general idea of when your time on this world is coming to an end? ☹️

I consider it neither. when I'm given a time limit I set a goal to exceed, That time limit was 6 months to a year. I have surpassed both. On October 18th, 2021, I have lived with ALS two years!

I take life as a challenge and a purpose. So when my purpose is done off to heaven I go.

#rockinALS #tamuraisadventure +fotografie

30a. (10. září 2021) What does ALS feel like?

Let me see if I can put it into words...

Hands, have you ever carried a heavy item and when you put it down your fingers won't move, they are stiff. After a moment they return to normal.

Well for me they don't, they remain stiff and very weak, I can't grasp or lift a pen with my left hand and a 1 pound weight in the right hand feels like 50 pounds.

Legs, when they aren't cramping they are weak and unresponsive. They don't respond to my desired requests. I stare at them trying to make movement and nothing happens except exhaustion. They actually feel as though I have 500 pound ankle weights strapped to each leg. My knees and ankles ache from the lack of muscles holding them together.

Eating, first off it is unavoidable that ALS takes the ability to swallow, however it begins with the tongue. You see the tongue becomes unresponsive and difficult to control. At this point imagine getting anesthesia in your mouth and your tongue is affected. In essence manipulation of food is challenging. This makes it difficult to move food away from the back of your throat causing frequent gagging. Now the epiglottis, the flap that separates your airway from your esophagus, well it starts to falter, allowing food to remain at the opening. This causes repeated swallowing and can lead to coughing and choking. Typically, pickles, dry goods, peanut butter, grapes, and cheese with cause this reaction.

30b. Laryngeal spasms, has your dog ever sounded like they are about to hack up a furr ball? That's a spasm, in a person it sounds very scary. Imagine getting the wind knocked out of you, when you try and take a breath you can't... that's what it sounds like.

Neck, many ALS patients lose muscle strength and tone in the neck as it progresses, thus needing neck braces or head restraints. Imagine having a 50 pound weight on your head, eventually you can't hold your head up. Many patients appear to be looking down constantly. Some become locked in this position.

Breathing, try this at home.

Gather the following: large shake straw, regular straw and a coffee stirrer. Now try this, take a normal healthy breath, now repeat breathing through each straw. You have just simulated progressive respiratory decline in an ALS patient. Now don't panic and catch your breath.

30c. Last exercise, now find a busy location in your home, sit in a chair and don't move or speak. Think of your favorite drink or snack. Now without speaking or moving communicate to your family that you would like that drink or snack. You want to get the real experience, try using a patient's eyegaze computer, let's time how long it takes to get frustrated? Imagine having to poop or pee. A typical person gets the feeling and goes. A person with ALS has to depend on others to get them strapped up in the sling for the hooyer and lift them out of the chair and on the toilet, fast enough, as there is no control of muscles in the rectum or the bladder anymore. The urge comes and it turns into a game show of the human claw machine over the toilet hoping there is no mess.

This is what ALS feels like to me.

#rockinALS #tamuraisadventure #alsissohard +fotografie

31. (4. září 2021) Did you know that when ALS progression increases the loss of energy it also decrease the ability to eat and drink properly.

Malnourishment and dehydration can cause baldness.

Before I got my feeding pump I could only eat 400-600 calories and drink about 30 ounces of water a day. Why not use your feeding tube? We did, however when you have ALS and a gastric sleeve you are at a higher risk. Using a syringe to provide fluids and nutrition was nearly impossible. I could only handle 120ml at a time. That is a half of a cup. Giving more caused reflux due to only having 20% of a normal stomach.

Now we are in a good position! Night two was great. My urine is flowing great and clear. 6 months of getting all the nutrition in 3 cups of Kate farms will hopefully clear up my skin and fill in my bald spots.

#rockinALS +fotografie a video

32. (19. srpna 2021) Choking has been an issue So crushing up the meds and putting them through my peg tube is the next the step. The weirdest part is tasting everything backwards. Because I have a small stomach it fills up quickly so instead of having the meds dissolved in my mouth the dissolved meds hit the bottom of my throat.
#rockinALS + fotografie a video

33. (5. srpna 2021) Yesterday and today I feel like I did just before my week in the hospital. I'm pretty sure I have a double ear infection. My mobility in my left arm is only 5%. Pushing buttons on my chair and even a TV remote. Just a week of being ill caused my progression to speed up. Due to the increased weakness bowel movements are not easy as I do not have the muscles to help. 8 days with miralax and benefiber. Bloating tight. Straightening my fingers is impossible, I choke on saliva, my water intake is horrible so I will need to use my tube for water. My calorie intake is 600-900 a day, so formula feeding is starting today. It's okay I got this and I made an appointment for my ears. Not whining just being honest and real. Getting sick just a little makes everything so much worse.
#rockinALS + 2 fotografie a video

34. (7. června 2021) Everything has been finalized on the new gadgets I will be adding to my chair. Unfortunately after I add the arm troughs it does add about 4 in additional to the sides and I lose the mounting features under the arms. So the only mounting part that we will have will be on the base of my chair which adds an additional two to four inches. Making it a little difficult to get through normal sized doors. The headrest will support my head so much better as I am experiencing head drop or that's at least what I call it very similar to foot drop. No more neck pain Hopefully and a more comfortable seating option with an amazing cool headband lol. Today we also got the Alexa ring and door opening device! This is super exciting because now is somebody rings the doorbell I can actually open the door for the person if I am alone. 🤖 Also I can go swimming! As long as we can get in with my hoyer and a beach chair. I just have to add a cute little attachment to my catheter.
#rockinALS #accessibilitymatters + 4 fotografie

35. (25. května 2021) Day 25- ALS Awareness Month.

Did you know that when an ALS patient loses their muscles due to the nerves dying that literally we are only skin and bones.

Never in my life have I had loose skin/ jiggly skin.

We can't just go get it removed or have it tightened up.

I wish I could share a photo with you of what my body looks like.(I do have one that I took this morning)

I saw myself in a full size mirror today and I am something that resembles a melting snowman. I mean it is warm here in Virginia but the body that I had worked so hard for is no longer the body I have now.

I have no muscle and when you lift one of my limbs or even my body the skin just hangs down over the bone and you can see what my bones look like.

This isn't to make you sad or upset nor is it a negative post. I just wanted to share an observation I saw this morning.

I'm an average girl 5'9 and 175 lbs and I'm melting.

#ALSAwarenessMonth #rockinALS #Everymomentmatters +fotografie

36a. (21. března 2021) How did ALS progress and how rapidly did it happen?

My ALS started before I even realized it. Someone from work actually noticed something was wrong. I started walking with a gait, this was noticed in the summer of 2018. In 2019 other things started to get worse, I would start to trip myself. The falls would start 1 or 2 times a week to up to 10-15 times a week. The falls started to get so bad I lost track and I would tan to hide the bruises on my legs and arms.

In January of 2019 I could not get my left foot to work when putting on shoes. By the summer of 2019 I had fallen in 1 year over 100 times, I started to favor my left leg more. By September of 2019 I lost full mobility of my left leg but could walk with a walker. When I had my diagnosis from Dr. Rock, I was then referred to ALS specialist and the best in Maine, there it was confirmed ALS.

In November of 2019, Dr. Taylor said walking is no longer safe and that I would need a wheelchair. I was still driving at that time as my right leg was still fully strong. By December of 2019 I stopped driving as I was lifting my right leg to push on the pedals.

36b. Jan 2020, I was fully using a motorized chair, unable to lift my arms above my head and lost more strength.
Feb 2020, No longer can walk even with guidance, but can stand. Can not swim without help. Showering with assistance and bathing.
April 2020, I now strain to talk and am on a ventilator for breathing at night and sometimes during the day if needed for exhaustion.
May 2020, I wear braces to help support my right ankle as now it rolls when I try to stand.
August 2020, I received my Trilogy Eye Gaze and will be practicing more for communication.
September 2020, I had surgery for the PEG tube (feeding tube) and Suprapubic Catheter. Lots of surgery complications.
In October 2020 , I was diagnosed with a severe DVT (blood clot) in my left leg and am no longer able to physically stand.
In January 2021, My breathing and strength has significantly decreased.
#alsawareness #rockinALS +2 fotografie

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	131
Text	Výpověď	Návštevy lékaře, prohlídky, operace	116

Text a multimédia	Výpověď	Sociální skupiny a jiné společenské akce	287
-------------------	---------	---	-----

Text a multimédia	Výpověď	Motivování ostatních členů skupiny	302
-------------------	---------	---------------------------------------	-----

Text a multimédia

Výpověď

Změna zdravotního
stavu pacienta

122

Text a multimédia

Výpověď

Motivování ostatních
členů skupiny

190

Text a multimédia

Výpověď

Návštěvy lékaře,
prohlídky, operace

248

Text a multimédia	Výpověď	Péče o zdraví, prevence	85
-------------------	---------	-------------------------	----

Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	333
-------------------	---------	--	-----

Text a multimédia	Motivace a pobavení	Zábava	58
-------------------	---------------------	--------	----

Text a multimédia	Výpověď	Zábava	76
Text a multimédia	Výpověď	Péče o zdraví, prevence	351
Text a multimédia	Motivace a pobavení	Kvalita zdravotnických služeb	313

Text a multimédia

Doporučení

Péče o zdraví, prevence

47

Text a multimédia

Výpověď

Pohyb a přemísťování (v
domácnosti)

403

Text, multimédia a odkaz

Doporučení

Pomůcky

224

Text a multimédia

Výpověď

Pozitivní události

96

Text a multimédia	Výpověď	Pohyb a přemístování (v domácnosti)	162
-------------------	---------	-------------------------------------	-----

Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	245
-------------------	---------	-------------------------------------	-----

Text a multimédia

Výpověď

Změna zdravotního
stavu pacienta

563

Text a multimédia

Výpověď

Pomůcky

148

Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	337
-------------------	---------------------	------------------------------------	-----

Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	180
-------------------	---------	----------------------------------	-----

Text a multimédia	Výpověď	Návštevy lékaře, prohlídky, operace	189
-------------------	---------	--	-----

Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	42
-------------------	---------	-------------------------------------	----

Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	209
-------------------	---------	-------------------------------------	-----

Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	284
Text a multimédia	Kombinace	Motivování ostatních členů skupiny	343
Text a multimédia	Výpověď	Péče o zdraví, prevence	384

Text a multimédia	Výpověď	Stravování	13
-------------------	---------	------------	----

Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	48
-------------------	---------	----------------------------------	----

Text a multimédia	Výpověď	Pomůcky	24
-------------------	---------	---------	----

Text a multimédia

Výpověď

Změna zdravotního
stavu pacienta

281

Text a multimédia

Výpověď

Změna zdravotního
stavu pacienta

146

Průměry na příspěvek: 213,4

Počet komentářů

23

Průměr reakcí: 213,4
Průměr komentářů: 38
Součet reakcí: 7682
Součet komentářů: 1368

37

44

30

22

24

16

77

2

11

44

41

17

38

43

71

32

35

64

71

9

11

19

Pacient 2

Počet příspěvků:	Muž
Přispívá:	20
Příspěvky:	Pacient

1. (26. květen 2021) My friend said she was about to do her least favorite thing- dusting. I told her to wear a mask. She asked, For dusting? My response was, I am not the one with a breathing problem. Oh, wait. I'm on a ventilator. How quickly, sometimes, we get acclimated to a situation and accept it as normal. Some people have an experience that is their normal that they have accepted as everyone's normal. Physical, emotional, and all the other abuses, are not normal. Please get help in breaking the cycle. There is an entirely different life awaiting you. Sometimes we settle for the familiar because we're afraid of the unknown. Embrace your ALS- Adjusting Life Style.

2. (24. květen 2021) The best part of waking up is the realization that I am blessed to be God's child. I contribute to the enjoyment of the day just by my attitude. Opening grateful eyes is a thrill from where my head rests each night. I am still working on seeing all the good possible in others. We are all blessed with some awesome opportunities. I once was blind, but now I see. Grace be with you, mercy, and peace, from God the Father, and from the Lord Jesus Christ. 2 John 3. KJV. ALS- A Loser Saved. Thanks, Zet.

3. (15. květen 2021) The experience of flying can be both exhilarating and frightening. Some people are visibly shaken when flying in a commercial jet. The take off and landing are foreboding to some people, while the rough air turbulence scares quite a few of us. However, the more we travel by air, the more we become comfortable with and understand and expect certain outcomes. We have traveled enough through this life to understand that certain parts of our journey will be bumpy. If it's raining when you look out of the window, climb higher than the clouds. The sun is ALS- Always Left Shining.

4. (6. květen 2021) Today I woke up refreshed and hungry. My appetite for food and life is undiminished. Once, getting up early and planting flowers was part of my enjoyment. However, it is a tremendous blessing to see all the beautiful flowers that I have a part in planting and God grows. I no longer own that home and involvement in flowers painting the yard is definitely close to nonexistent. Now, amazingly, I have been blessed to plant words into the minds of many and I enjoy beholding what the Gardener of all of our lives grows. Painting lives with broad strokes of love and encouragement are superior to the botanical experience. I'm grateful for the opportunity of ALS- Always Loving Someone.

5. (24. duben 2021) I'm no longer able to take my car in for a tuneup. Who doesn't appreciate a smooth running vehicle? Unfortunately, we sometimes get accustomed to chugging along because the change is imperceptible until the the loss off power is unmistakable. Similarly, our thinking can get into rough running as opposed to the purring of peace that passes reasonable understanding. I'm getting a mental tuneup this month. I have a lot of road and life to cover. ALS- A Long Stroll. Thanks, Bena.

6. (21. duben 2021) It's been a couple of years since I exclaimed, Hold my mule while I shout. I am in love with the Creator above what He's created. I would like to continue to praise our God for His Word being sure. Though the financial entity played a part in our new mule back then, a new Toyota Sienna, I am banking on Jesus. He is where I have confidence, and from Whom all blessings flow. I'm careful to praise God with a grateful voice and heart for moving to a facility closer to my family and with a private room recently. Then shalt thou delight thyself in the Lord; and I will cause thee to ride upon the high places of the earth, and feed thee with the heritage of Jacob thy father: for the mouth of the Lord hath spoken it. Isaiah 58:14 KJV. I am the Lord: that is my name: and my glory will I not give to another, neither my praise to graven images. Isaiah 42:8 KJV. ALS- A Lifelong Song. Thanks, Joann. *+fotografie*

7. (12. duben 2021) I no longer wear nice suits. My wife would occasionally buy me a suit that looked great and as I slipped it on, it just felt fantastic. No matter how little money I had or what else was going on, I could put on the suit and I felt like things were popping. What is the expression? I felt like a million dollars. Well, I no longer dress up with clothes. I mainly wear a smile to dress up and I slip on an attitude of gratitude. Talking about bling, bling- I am told at times I radiate with happiness. It is said nobody can be that happy all of the time. I agree, nobody can, but this somebody has chosen to be happy even now by the grace of God. I chose ALS- Alternative Lifestyle Spectacular. I'd send you a brochure, but I'm not selling anything. However, I am sold on it.

8. (8. duben 2021) I'm loving how many of my age are now cruising into retirement. How awesome to work and reach some level of accomplishment that now it is rest time. Not just the kick up your heels rest, but what will you do with the REST of your life. You have definitely earned the right to chill. However, there is a world gone mad that could use our perspective, discernment, compassion, and godly love. Enter to learn; depart to serve is now available. When we had a job, we were limited. Before our lights grow dim, let's light it up for Jesus with no limitations. ALS- A Living Servant. To them God has chosen to make known among the Gentiles the glorious riches of this mystery, which is Christ in you, the hope of glory. Colosians 1:27 NIV.

9. (6. duben 2021) I am grateful for many things, but one day I was wonderfully surprised by one of my former care givers dropping by with gifts. She and her son had picked out jerseys of the Anaheim baseball and hockey teams for me. You sometimes read stories of my experience. Praise God for those who are a positive impact in their caregiver responsibilities and services. I am so grateful for the good ones. And, thanks be to God for the bad caregivers that increase our prayer lives. Pray without ceasing. 18 In everything give thanks: for this is the will of God in Christ Jesus concerning you. 1 Thessalonians 5:17-18 KJV. ALS- Appreciating Lovely Surprises. Thanks, Tonya.

10. (2. duben 2021) I finished listening to a book about gratitude, Gratitude: A Way Of Life by, Louise L Hay. Now I know better why I am so happy. It turns out that being grateful is huge in just about every aspect of life. I've mentioned how re-framing is monumental in getting past the earlier experiences in life that were harmful, hurtful, and devastating. Being grateful is like a superpower that doesn't cover up or ignore the unpleasant incidents in life but rather embraces them and finds what is a positive and beneficial reason to be thankful because of them. I admit that it can be a stretch, but that is a characteristic of the Fantastic Four. Not the Marvel comic book team. I'm talking about the Father, Son, Holy Spirit, and you with ALS- Attitude Leveraging Superpowers.

11. (23. března 2021) Don't let your pain, struggle, or trial be wasted. Someone may benefit from your empathy because you have traveled similar roads. Every journey is different, but our challenges often band us together.

I remember being asked by a friend what were some of my signals that I had ALS? I hated that he joined me in the fight against giving into this monster, but I was glad I could help encourage and support him until he finished his last round. I just love how God has pulled it altogether in my life that none of my pain has been wasted.

I also one day recognized the pain and frustration in the voice of a coworker when I said, "Good day mate." Her response of, "There's nothing good about it" caused me to zero in and reflect that I had a day like that going through a divorce. She said, "Bingo! " I tell you, it took every thing in me to hold back my tears for her until another time when I invited her to lunch so she could vent.

It's a good thing to not waste our experience when it can make us better and someday bless someone who could use some understanding support. Whenever possible, be ALS- Another Life Support. Making my hurt some good is so good.

12. (19. března 2021) Life is good. I didn't receive any items left at the old place, so I will have my wife buy more. She does my laundry now so I am no longer hunting for things.

It's a tremendous task getting everyone here at the new facility familiar with me at one time, especially when they have not had a ventilator resident in about two years. We are making great progress.

Helping the kitchen with time, temperature, texture, and taste will be ongoing for a while. I'm excited that they have ordered my eggplant online and purchased an air fryer. It is awesome having my wife's food, cakes, and pies. Fettuccine, broccoli, and peach cobbler will be today.

I leave my blinds open and the morning sunlight comes in. I see my wife or daughter four times a week. The view has significantly improved with their smiling faces.

Currently, I am not allowed to go to the bathroom without a therapist present to transfer me. Bummer, but it will take a while for them to feel comfortable with what I can do safely during the transfer from the bed to the commode chair and rolled to the bathroom for ALS. Fill in the blanks.

13. (16. březen 2021) Thanks for your prayers and well wishes. I definitely have a more responsive director and assistant. People are trying to learn how to care for me.

I like the plans with the therapists and how I finally am getting a more consistent movement of my arms every two hours and range of motion twice a day soon.

The cooks will improve as I give them feedback for how to prepare my food. Of course, it's great having my wife bringing me food also, including some of her pies and cakes.

Having a private room is definitely also wonderful. My daughter's visits are special along with my wife's. So, I see one of them on Sunday, Tuesday, Thursday, and Saturday.

I'm on book reading for the year number 53. Life is still good in Jesus. +2
fotografie

14. (8. březen 2021) I'm doing my normal well with the exception that I was med flight transferred from Fresno to Garden Grove, CA on last Tuesday. From the time I left the facility, I was in the air within 45 minutes.

I am definitely loving my private room. So far I love the DON and RT. I'm working with the PT to get evaluated so I can be allowed to be more mobile. Today I did get on a table that rotated to different upright degrees to walk in place safely.

They have not had a ventilator resident for a couple of years, so most of the nurses are learning that as well as becoming acquainted with me.

The cook is preparing my food nicely but too much of it. So far I am pleased with the timing and taste. They bring little packets of salt and pepper so that helps tremendously.

I have immediately asked for attention to the hydro bath, but when I got in it today it didn't meet my needs.

The Activities Coordinator washed and vacuumed my wheelchair the same day I arrived.

I'm enjoying my wife's cooking already. Yesterday I was brought a lemon pound cake. Kayla's visit Saturday was also sweet. +*fotografie*

15. (4. září 2020) The loss of breath and the desperate desire to have more of them is a glimpse of the craving for life and living some feel as ALS slowly takes away the ease of breathing and living life. It's unreal how dialed in is the precious awareness of what is important- the certainty and clarity are unbelievable. It becomes a time to maximize some relationships and to cut loose others. I know I checked on my insurance and was totally confident in my Blessed Assurance. Knowing how much is in the bank is great, but for me, knowing my name is written "there" has given me peace in the midst of the storm. ALS- Am Loving Solace. Thanks, Sandy.
+fotografie

16. (1. září 2020) Don't be a co-star in your own life. Take center stage with a commanding presence. I'm bedridden and unable to move, and yet, I am still a mover and shaker. It has been said that I intimidate people. That is funny to me. My stance is to self-advocate for my health care excellence. I am relentless and thorough in my observations. Tempering my frankness, I still get the message across. Nothing makes me happier than saying, "Good job." People respond better when they are appreciated. We are all learning together. Help me help you. I loved it in the movie, and I am excited to make things happen in my life. I'm my own CEO- Chief Encouraging Officer with an ALS- Awesome Life Shared. Thanks, Stella.

17. (30. srpen 2020) August has been another awesome month. I enjoyed participating in the ALS Fundraiser for a cure and treatment. I also joined another awesome support group on Facebook. I'm feeling good about how many people actually take time to care about others, and the surrounding support of shared experiences is phenomenally exhilarating. We are not alone. When you take the time to reach out, you make a difference. This world becomes a better place. Thank you for being an ALS- Amazing Light Source. Thanks, Julie.

18. (28. srpen 2020) Okay, let's get this party started. Today is the day, eleven years ago, that I received my diagnosis of ALS. Well, to be clear, I am celebrating life. Even with many dimensions diminished, I am living a full life. If the essence of existence is loving and being loved, I am totally there. If the meaning of life is caring and sharing, every day brings me the opportunity to fulfill this purpose. So, as a prisoner bound by the chains of immobility, I daily take my walk of faith. I don't take it for granted that the ventilator pushed air helps my lungs to expand. Whatever muscles still responding to my mental commands are occasions for an emotionally happy dance. Don't get it twisted- this is hard stuff with a physical disability. However, I have been battle-worn and I refuse to concede to the loss of any mental or spiritual ground I have gained. Today, party with me, and if you haven't already, get your party started with ALS- Amazingly Lighthearted Spirits.

19. (27. srpen 2020) There, I said it, ALS. Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's Disease. I'll always have a hard time spelling it, but when spelled out, it is a neurodegenerative disease that affects the nerve and muscle slowly for some, and more rapidly for others, to the point, most voluntary functions are eventually lost. A captive to a dysfunctional body, some give up or out and die within a few years of diagnosis. What you think and what you believe comes quickly to the forefront! Eleven years ago, I heard the sad and serious tone of my Neurosurgeon doctor who assisted in my journey of getting a correct diagnosis. I laughed and said, "At least I don't have to have surgery." I could laugh at death because to me ALS meant A Loving Savior! I'm in His care and He has the last word concerning my life temporal and eternal.

20. (27. srpen 2020) Hello everyone. I'm Chris in Central California. I was diagnosed eleven years ago this month. I live in a sub-acute facility and for the most part, it's a good life. I post daily, have a website, and have compiled four devotionals. My family is 280 miles away waiting for my transfer to take place to a facility 30 miles from our new home. My wife is retired and my daughter just graduated from the nursing program at Loma Linda University. She takes the state boards next month. Recently, I completed 800 hours as a Crisis Text Line Counselor. I'm awaiting a virtual position with the Veterans Crises Line. My faith is strong, my health momentarily plateaued, and to my knowledge, my mental health is good. I have been on a ventilator for 3 years. I have a G tube but I eat solids for two meals a day. I believe in ALS- Always Lifting Someone. *+fotografie*

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text	Motivace a pobavení	Péče o zdraví, prevence	12
Text	Výpověď	Motivování ostatních členů skupiny	79
Text	Výpověď	Přemístování (mimo domácnost)	25
Text	Výpověď	Zábava	85

Text	Výpověď	Myšlenky, psychologie	28
------	---------	-----------------------	----

Text a multimédia	Výpověď	Myšlenky, psychologie	37
-------------------	---------	-----------------------	----

Text	Výpověď	Oblékání	138
------	---------	----------	-----

Text	Výpověď	Stárnutí a umírání	17
------	---------	--------------------	----

Text	Výpověď	Výběr pečovatelů a zdravotnických zařízení	195
------	---------	--	-----

Text	Doporučení	Myšlenky, psychologie	24
------	------------	-----------------------	----

Text	Motivace a pobavení	Motivování ostatních členů skupiny	27
------	---------------------	------------------------------------	----

Text	Výpověď	Osobní hygiena	35
------	---------	----------------	----

Text a multimédia	Výpověď	Výběr pečovatelů a zdravotnických zařízení	232
Text a multimédia	Výpověď	Přemísťování (mimo domácnost)	30
Text a multimédia	Výpověď	Sociální skupiny a jiné společenské akce	108

Text	Motivace a pobavení	Motivování ostatních členů skupiny	259
Text	Výpověď	Sociální skupiny a jiné společenské akce	24
Text	Výpověď	Motivování ostatních členů skupiny	159

Text

Výpověď

Předání osobních
informací

110

Text a multimédia

Výpověď

Předání osobních
informací

487

Průměr reakcí: 105,6
Průměr komentářů: 16,75
Součet reakcí: 2111
Součet komentářů: 335

Počet komentářů

0

11

1

12

1

0

31

0

5

2

2

6

34

1

27

41

0

31

19

111

Pacient 3

Počet příspěvků:

Muž

Příspěvá:

22

Příspěvky:

Pacient

1. (11. března 2022) One of my friends got me the best shirt ever!
+fotografie (zobrazující fotku osoby s vtipným nápisem)

2. (26. únor 2022) The VA rules! Just got my custom AFO's and they actually made them camo to match my power wheelchair! Standing is easy again! *+fotografie*

3. (17. únor 2022)



4. (16. únor 2022) Practiced with the Tobii machine today!! It's crazy the technology that has been created to help us! Despite the horrible disease, I am thankful to benefit from all the technology created to keep me functioning with it! *+3 fotografie*

5. (9. únor 2022) Found a guy on Etsy who 3D prints joystick toppers, got a few made of my favorite hero/character: Judge Dredd! The wife did the great paint job! +2 fotografie



6. (21. leden 2022) Got a new toilevator so my wife doesn't blow out her back trying to lift my big butt off the toilet anymore! + 2 fotografie

7. (7. prosinec 2021) Ain't no ALS slowing my roll! 70 mph down desert trails in a UTV today! Fuck ALS!!! +video a 10 fotografií

8. (14. říjen 2021) Okay, so I have the problem with easily triggered laughing, psuedo bulbar affect. Makes reprimanding or having serious talks with our two young kids almost impossible. So the doc gave me Neudexta.

Then I read the label. It cautions you against taking it with marijuana, which I do medically. Marijuana is actually quite helpful in helping me sleep and when I take it during the day it definitely helps control my tremors and helps make my motions smoother and more coordinated. Has anyone here been on Neudexta and marijuana at the same time? What were the reactions if any? And for anyone who just takes Neudexta, how well does it work for you? Is it worth it?

9. (10. říjen 2021) From the cold south rim of the Grand Canyon to water tubing and water skiing in the same week! Gotta love Arizona's different climates!

Thanks to Arizona Adaptive Water Sports (AAWS) my family got to have an awesome day on the water! I got to do the water tubing and water skiing, and the kids and wife got to go kayaking, swimming and using a water slide off a double decker party boat. My son's favorite dive is called "The Starfish" +15 fotografií

10. (6. říjen 2021) Got to do a day trip to the Grand Canyon and Sedona yesterday with the family! And what a gorgeous day for it! +10 fotografií

11. (1. říjen 2021) So just a question:

I spent the past two months dealing with kidney stones, dual stents and 2 surgeries. This has led to me being in a huge amount of pain, and to deal with it, I slept in my power wheelchair for the majority of the time.

Now in that time my wife bought Sleep Number mattresses for us, we each have a twin xl with the motorized bases where the head and feet can raise and lower. The new mattress is about 2 inches lower than the old one, apparently that is too low for me to be able to get up off it to transfer to my wheelchair.

So then we put the extended legs on the base, lifting the bed approximately 6 inches up. Now it is life-threatening to try to get into. My wife usually lifts my left leg up onto the bed then I roll up into bed. Now with it higher, I feel like I am doing a split and my leg feels like it's going to pop out of the socket.

How do other people here get their loved ones onto the bed in a situation like this? I would like to continue to try to transfer myself as long as possible, and I hate being scared of my own bed. 😊

12. (6. září 2021) Hell everyone! So I have a question:

I live in Arizona, and as some of you may know, it gets a little warm out. I use a Quantum Edge 3 power wheelchair to get around. Whenever I find myself outside (like at a block party we were having today) even if I am in the shade, my joystick controller gets NUCLEAR HOT!!! Almost to the point it's too hot to touch, that can't be good for the electronics.

Does anyone know of a cover or something to prevent this?

13. (24. srpen 2021) Public service announcement:

Drink lots and lots of water! Stay away from sodas and energy drinks all the time like I did.

Apparently being wheelchair bound makes you more susceptible to kidney stones, as you are not bouncing around on your feet all the time like you used to.

Had to go to the ER on Sunday night for continued kidney stone pain that I got diagnosed with two weeks ago and it still hadn't passed. They did a CT Scan and found out it wasn't 4mm like the other ER had estimated 2 weeks ago, but instead 6mm x 3mm, and was currently stuck between the bladder and kidney and wasn't going anywhere. So I got to do an emergency surgery to put in a stent. 😊

Now they are going to have to go in again and break it up with a laser and remove the stone, then remove the stent at another date after that. I should have just drank more water 😊

And of course the doctors wouldn't let me take my riluzol or baclofen while I was recovering so I was stiff as a board and shaking like a leaf the whole time at the hospital.

All in all, ALS + Kidney stones = hell on earth!

14. (12. srpen 2021) Last month (the whole month) I had and beat pneumonia.
Today I just got my first ever kidney stone.
This is just not my summer!

15. (5. srpna 2021) I try hard every day to find something I have done to be proud of...
Today I vacuumed a couple rooms in our house while motoring around in my power wheelchair. It was then when I realized that for those few fleeting moments, that I had become the world's most expensive Roomba.

16. (28. červenec 2021) So, food for thought: And I am by no means a medical professional or offering medical advice! But I have a theory that backs up a thing I heard from my physical therapist today.
Today my PT came and we have been discussing supplements and stuff that may help me with slowing progression and possibly maintaining muscle. The supplements B12, L-Carnatine, Taurine, creatine, etc came up in his recommendations to me...
Then I remembered, I had been addicted to energy drinks from 2005-2018. I averaged about 2-4 drinks a day. Monster, Red Bull, Rockstar, NOS, etc. funny thing: I decided around late August 2018 to break my addiction once and for all...then my foot drop and limping began in October 2018...
Now pretty much all the supplements my PT mentioned are main ingredients in energy drinks! Is it possible that my daily consumption of those energy drinks was delaying the onset of my symptoms by providing me with a daily dose of those supplements? And now I will be continuing my addiction anyway because I need to get those supplements now anyway, and screw it, why not drink the stuff anyway, not like I am too worried about the long term health effects (just saying ♂).
Just food for thought, wonder what anyone else thinks. (PS: I am 36 years old, onset was 34)

17. (13. červen 2021) Just got my first bottle of ReQuip CR from my doctor to start taking tomorrow. Anyone here have any experience with this med? Hoping it helps slow progression as some research has suggested.👀

18. (31. květen 2021) Took the family out to Monster Jam today. ALS sucks, but I will tell you what doesn't: front row parking and a private balcony for wheelchair access for the family! I will never let ALS stop me from having fun!!! +14 *fotografi*

19. (13. duben 2021) When getting a power wheelchair, always opt for the PosiTraction option....🤖
This is why I can't be trusted with nice things. +3 *fotografie*

20. (17. březen 2021) Just got these sheets, hopefully no more wrestling with a bundle of crappy sheets wrapped around my legs halfway through the night! +3 *fotografie*

21. (5. březen 2021) Well CVS, I don't think I will be running out of Baclofen anytime soon.... 🤖 +fotografie



22. (12. únor 2021) Absolute game changer when the dexterity in your dominant hand is diminished!! I have never used a bidet before, and was very nervous spending this much money, but it was ABSOLUTELY worth it!!! +fotografie

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text a multimédia	Motivace a pobavení	Zábava	1427
Text a multimédia	Motivace a pobavení	Pomůcky	159
Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	390
Text a multimédia	Výpověď	Pomůcky	314

Text a multimédia	Motivace a pobavení	Zábava	103
Text a multimédia	Doporučení	Pomůcky	230
Text a multimédia	Motivace a pobavení	Zábava	133
Text	Kombinace	Užívání léků	8
Text a multimédia	Výpověď	Zábava	191
Text a multimédia	Výpověď	Zábava	230

Text	Kombinace	Pomůcky	1
------	-----------	---------	---

Text	Kombinace	Pomůcky	0
------	-----------	---------	---

Text	Doporučení	Péče o zdraví, prevence	27
------	------------	-------------------------	----

Text	Výpověď	Změna zdravotního stavu pacienta	32
Text	Výpověď	Uklízení a udržování domácnosti	117
Text	Výpověď	Stravování	8
Text	Kombinace	Užívání léků	1
Text a multimédia	Výpověď	Zábava	445
Text a multimédia	Motivace a pobavení	Zábava	108
Text a multimédia	Doporučení	Pomůcky	10

Text a multimédia

Výpověď

Užívání léků

31

Text a multimédia

Doporučení

Pomůcky - toaleta

126

Průměr reakcí: 186,0
Průměr komentářů: 21,45454545
Součet reakcí: 4091
Součet komentářů: 472

Počet komentářů

102

6

29

29

7

32

9

13

30

22

9

1

7

6

15

9

0

44

32

7

13

50

Pacient 4

Počet příspěvků: Muž
12
Přispívá: Pacient
Příspěvky:

1. (1. březen 2022) Happy pancake day everyone!
Today I am launching my next challenge, I am going to transform myself into an Easter MND bunny. My aim is to spread awareness of this disease and at the same time delivering Easter gifts to children in my local area. Weather permitting I will be out on my scooter delivering gifts. If you would like to donate Easter eggs or Easter gifts that would be great. Children have had a tough few years and with everything that is going on at the moment it will be lovely to bring a smile to so many faces.
Watch this space to see me dressed as the MND Easter bunny
👉just waiting for my costume to come through. +2 fotografie

2. (27. únor 2022) I just wanted to say Thankyou to everyone who sends me such lovely messages. I am often told I am inspirational but your messages really inspire me Thankyou 🙏
🙏🙏🙏🙏 +video

3a. (25. únor 2022) I think we are all thinking the same watching the horrific events happening in Ukraine.
I really didn't think I would see this again in my lifetime. So I wanted to share with you a message I had today, I have had permission from the sender as long as I deleted the names. What this shows is that we can't control everything that is going on, but a little bit of kindness can make a difference to others.
Hi John
I just wanted to send you a personal message to let you know what you have done for me.
My beautiful husband passed away 14 months ago from the beast MND. I have not got over the fact that our future together has been taken away.
His final wish was for me to scatter his ashes in one of our favourite places. I have not had the strength to do this as I felt I was letting him go.

3b. I have been following your story and some days you make me laugh some days you make me cry. The one thing you have done for me John is give me strength, after all if you can keep smiling so can I.
Yesterday I put your photo on my screensaver on my phone and drove to our special place. I let him go and all the time I looked at your photo and told him all about you.
I feel so much better now I have carried out his final wish. Today I have found the strength to sort through his things to donate to other sufferers.
Never under estimate how much you help others John , I am now on a mission to stand by your side and raise funds to find a cure.
Keep smiling, keep fighting and Thankyou from the bottom of my heart for helping me to take a more positive direction.
You are a true warrior and loved by so many.
Forever grateful

4. (24. únor 2022) After a successful few days of exercise 🤔 I thought I would try out my new mankini and go for a run. (Not really me in the picture but I thought it was funny) +2 *fotografie*

5. (22. únor 2022) Yesterday I set myself a challenge to walk 10 steps with my walking frame ! and I did it 🤔very proud of myself 😊set yourself a little challenge today it certainly makes you feel more positive 🤔🤔🤔
#PositiveVibes
#everydayisablessing +2 *fotografie*

6. (20. únor 2022) Drum roll 🤔😊😊
We have just counted the valentines cards and I have received an amazing total of 441!!
Thankyou so much everyone ♥ I have loved reading every single one ♥ I don't know what I will do with myself tomorrow I look forward to the postman coming 🤔 maybe my next challenge should be how many birthday cards I receive 🤔😊😊
We have raised 441 x £5 = £2205
For MND research and all the stamps have gone to Stamp Out Mnd
♥♥♥♥♥♥♥♥♥♥♥♥♥♥♥♥ +4 *fotografie*

7. (19. únor 2022) What a windy day yesterday! My wig blew off 🤔 and look what I have now 😊😊 +2 *fotografie*

8. (18. únor 2022) To all my warrior friends who have catheters remember this 🤔🤔



9. (17. únor 2022) I have been very busy today ordering a few things for my summer collection

🤔🤔🤔🤔🤔

🤔🤔🤔🤔🤔 +3 fotografie

10. (16. únor 2022) I started in November on a campaign to raise awareness and to raise funds for research into this horrendous disease. I have set numerous challenges and I have raised an amazing £11,500 🤔 my recent goal was to receive as many valentines as I could , as I was being sponsored £5 per card! I have received over 300 cards ! Together we have to fight on 🤔

Sending valentines love to you all ♥♥♥♥♥♥♥♥

<https://www.justgiving.com/fundraising/John-adams44> +3 fotografie

11. (16. únor 2022) Sorry everyone 🤔 the Alliens are coming 🤔🤔 +2 fotografie



12. (15. únor 2022) Good morning all my warrior friends ☺️ it is a horrible day here in the uk 🌧️ I am looking forward to seeing a bit of sunshine ✨

🤔🤔🤔🤔🤔🤔🤔 +video

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text a multimédia	Motivace a pobavení	Zábava	35
Text a multimédia	Výpověď	Vděčnost za existenci skupiny a poskytnuté rady, podporu	360
Text	Výpověď	Motivování ostatních členů skupiny	76

Text a multimédia	Motivace a pobavení	Zábava	340
Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	125
Text a multimédia	Motivace a pobavení	Vděčnost za existenci skupiny a poskytnuté rady, podporu	60
Text a multimédia	Motivace a pobavení	Zábava	223

Pouze multimédia	Motivace a pobavení	Zábava	36
Text a multimédia	Motivace a pobavení	Zábava	389
Text, multimédia a odkaz	Výpověď	Pozitivní události	99
Pouze multimédia	Motivace a pobavení	Zábava	81
Text a multimédia	Výpověď	Motivování ostatních členů skupiny	221

Počet komentářů

6

Průměr reakcí: 170,4
Průměr komentářů: 23
Součet reakcí: 2045
Součet komentářů: 276

76

10

23

15

6

18

8

46

6

6

56

Pečovatel 1

Žena

10

Počet příspěvků:

Přispívá:

Pečovatel (manželka)

Příspěvky:

1. (28. srpna 2021) My Johnny gained his wings 8 days ago. I feel as though I'm simply going through the motions in everything that I do. Like none of it is actually taking place. This disease took away the love of my life. The loss is incredible....

2. (19. srpna 2021) Had a tough day today. Everyday is tough, to some extent, but today was more so.
I wore myself out, mowing the lawn, cleaning the house, that when it came time for unexpected ALS craziness, I was exhausted.
I'm finally sitting down and relaxing since being on my feet since 10a.
Felt bad for my PALS, as I had a bit of crying spell. Feeling sorry for myself.
Trying to tend to him while he was laying down flat, which makes it hard for him to breathe. It was tough.
Pals looks diff today. More pronounced cheek bones, which means more sunken in cheeks and temples. So sad....
My Pals told me "I did good". I don't get that too often, so I'm rewarding myself with a bag of starburst.
Oh, who am I kidding...I eat them almost nightly.

3. (3. červenec 2021) My Pals has changed, or declined quite a bit in the last month. I feel as though once he got his feeding tube. Not saying that the tube has anything to do with the decline, it's just a time marker.
Extremely tired
Restless
Moans nonstop
Legs and feet are hurting him badly
Looks so much more weak
Barely wants to leave his bed for the recliner
Barely smiles anymore
It's just heartbreaking

4. (3. červenec 2021) Does anyone know of a group of Soldiers(or veterans) that were diagnosed while still on active duty(enlisted)?

5. (28. březen 2021) I do not have a cough assist
Pals is trying to cough up phlegm,
How can I help???

6. (28. únor 2021) Hey all!

Question?

My Pals has been coughing lately. He claims it's a "tickle" or feels like a small chunk of something that he's not able to get out.

It seems to be mostly when he eats or drinks.

He will cough, over and over, and at times look as if he is dry heaving. Or coughing and can't get his breath. I'm not sure if I'm describing it correctly. Is this him starting with the swallowing, cough, goop?

Ty

7. (11. prosinec 2020) Question for y'all?

My Pals presented in his arms and legs first. His speech started changing around Feb of this year. He mentioned to me tonight that his bottom lip is numb. I assume this is a normal part of the disease? I guess for me, I'm curious/scared if this is him progressing in those crucial areas?

8. (29. únor 2020) On a lighter note, I ordered these 17 inch bendy straws that open to 20 inches for John to drink with. He can't lift a glass or sit up and raise his arms to guide the straw, and can't reach the little straws.

They are called Mammoth. [??????](#)

9. (29. únor 2020) Haven't posted in a couple of days. It's been a tough couple..

We had been trying to get into the ALS clinic in Memphis. They couldn't get us in until May, and the Chattanooga clinic, not until August. As we all know, many ALS wouldn't make it to those dates.

BUT, we had an Angel manage to get us in, in a month. Our appt was this last Thursday. Amazing, caring, understanding, supportive, knowledgeable staff. The first time I think we felt, good after a visit.

John took a pretty nasty fall at the clinic. Hit his head so hard, you prob could hear it a block away. Needless to say, we were sent to the ER for a CT scan to rule out any brain bleeds, etc.

John is ok! Nothing wrong with his head!!!

Me, on the other hand, broke down as soon as we were alone, headed to the ER. Out of pure exhaustion, desperately wanting to be at home, relaxed, etc. I just didn't know if I had it in me, to cont on that evening. I began to question my strength(mental, emotional, physical, spiritual), my abilities to care for other human beings. sometimes, I believe we question our very own existence.

10. (24. únor 2020) I don't normally share anything too personal. But I am learning that in order to get our Nation to understand the crippling severity of ALS, I need to be a bit more open.

I know one thing I miss being a caregiver of a Pals, is a hug, a tight embrace from my husband. It can be reassuring, supportive, warm, etc These are things that we take for granted every day. But when you can no longer have these, it affects you greatly. We understand that we are loved, but sometimes we just need that embrace.

This morning, I crawled back into bed and placed his arms around me. It was so very special and so very much needed, for both of us. Missing his arms, his strength!

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text	Výpověď	Stárnutí a umírání	194
Text	Výpověď	Změna zdravotního stavu pacienta	166
Text	Výpověď	Změna zdravotního stavu pacienta	106
Text	Dotaz	Vyhledání pomoci	0
Text	Dotaz	Pomůcky	14

Text	Dotaz	Péče o zdraví, prevence	10
Text	Dotaz	Změna zdravotního stavu pacienta	5
Text	Motivace a pobavení	Zábava	126
Text	Výpověď	Výběr pečovatelů a zdravotnických zařízení	60

Průměr reakcí: 84,2
Průměr komentářů: 36,8
Součet reakcí: 842
Součet komentářů: 368

Počet komentářů

61

42

33

5

43

53

23

30

52

Pečovatel 2

Muž

Počet příspěvků:

15

Příspívá:

Pečovatel (přítel)

Příspěvky:

1. (10. březen 2022) When you go from long term disability to social security disability insurance. What's the difference is pay and service?

My gf is looking into a health insurance as well.

2. (17. únor 2022) Has anyone that takes or taken trazodone also taken cbd and or thc?

Any bad affects?

3. (15. únor 2022) Has anyone ever worked by using the eye gaze? My gf/pALS is a copywriter and would like to go back to it until she totally can't.

I was wondering if you can use it for work.

4. (7. únor 2022) A little gross but my pALS is unable to use her hands. She's been having trouble getting dry nose gold out and is using q tips. I was wondering if there's anything that we can use instead?

5. (2. únor 2022) Has any pALS gone full vegan? Mine is and she's losing way too much weight.

Good? Bad?

I think we are going back to meats like turkey and chicken.

6. (6. leden 2022) I'm in search of a nurse practitioner that can come to the home and administer an antibiotic for lyme. Tampa, Florida area?

Any suggestions?

7. (17. prosinec 2021) I'm thinking of a way to get my pALS gf on my insurance. She's too young for Medicare and I don't think she'll be able to get medicaid.

I'm thinking the only way is marriage but I'm hesitant. Has anyone done this?

8. (3. prosinec 2021) Has anyone in this group been to body science in florida?

Pros cons?

9. (3. prosinec 2021) What's a good product to help pALS hold onto utensils better?

10. (11. listopad 2021) At what point did you have to talk to your pALS about getting outside assistance?

Thinking a nurse for an hour or two a day.

11. (17. říjen 2021) I'm a bf for my als gf. I feel like I'm becoming more of a caregiver now and it's difficult to transfer back and forth.
Has anyone experienced this?
Do you become less of a partner?

12. (22. září 2021) My pALS is having a stretching or turning feeling in her muscles while she sleeps.
The cramping has been better but how, if we can, do we control the stretching feeling?
Has anyone experienced this feeling?

13. (31. červenec 2021) Any tips on decreasing muscles cramps/stiffness at Night?
My gf is 43 with als. Still gets around but gets very stiff at nights and sleeping is difficult.
I massage her once a week but is there anything I can give her that would help the muscle stiffness/cramping at night?
Btw this group is great. The disease effin sux

14. (29. červenec 2021) Not trying to have a political reaction or argument.
Has your doctors recommended getting the covid vaccine?
Has any als patients gotten it ? And what was your experience?
Thanks

15. (25. červenec 2021) How have you dealt with a loved one that totally doesn't believe or want to believe they have this?
We are going the remedy, supplement route but maybe med trials would be better?

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text	Kombinace	Vyhledání pomoci	0
Text	Dotaz	Užívání léků	0
Text	Dotaz	Pomůcky	1
Text	Kombinace	Změna zdravotního stavu pacienta	8
Text	Kombinace	Stravování	8
Text	Dotaz	Výběr pečovatелů a zdravotnických zařízení	3
Text	Kombinace	Výběr pečovatелů a zdravotnických zařízení	7
Text	Dotaz	Kvalita zdravotnických služeb	7
Text	Dotaz	Pomůcky	3
Text	Dotaz	Vyhledání pomoci	5

Text	Kombinace	Negativní pocity pečovatele	19
Text	Kombinace	Nespavost a poruchy nočního chování	0
Text	Kombinace	Nespavost a poruchy nočního chování	20
Text	Dotaz	Péče o zdraví, prevence	4
Text	Dotaz	Vyhledání pomoci	5

Průměr reakcí: 6,0
Průměr komentářů: 24,6
Součet reakcí: 90
Součet komentářů: 369

Počet komentářů

15

9

0

34

62

12

71

20

19

13

27

0

70

13

4

Pečovatel 3

Žena

Počet příspěvků:

15

Přispívá:

Pečovatel (dcera)

Příspěvky:

1. (14. březen 2022) I am leaving this group so that I can properly grieve my loss. I'd love to stay and offer advice, however, I need to separate myself from the reminders of this awful disease. I pray for continued patience, love, and hold on strong to your faith. This group has been very helpful. Continue to pay it forward.

2. (10. březen 2022) About 7 or 8 years ago, when my mom was 79/80 years old, she used to randomly drop things that she was holding, for no reason. She would get so upset. We used to say "You're getting old mom. Those things happen." Well those things don't happen unless something is wrong. In 2018, she started losing a lot of weight without trying. In 2019, she started losing her voice and the use of her left hand. In 2020 she was diagnosed with ALS. On Feb 1, 2022, at the age of 86, she was set free. Her dropping things was only the beginning of this disease.

3. (9. březen 2022) What I've learned about this awful disease is everyone's symptoms can be completely opposite of someone else's. I've been in this group for about 2 years while caring for my Mom. I see posts about thickening mucous; my mom had issues with watery saliva. I see posts where PALS are able to do their own suctioning but couldn't walk; my mom could barely raise her arms, barely use her hands, and couldn't extend her fingers, but was able to walk. I saw posts about people not being able to blink or close their eyes; blinking was one of the last things my mom was able to do before she passed away. There's so much more, but these things weigh heavy on my mind when I see these posts. I feel terrible that anyone has to go through this. PALS & CALS, I pray for your strength, patience, spiritual guidance, and Love. ???
CALS, stay strong.
PALS, keep your faith. It will get you through to the end.

4. (3. únor 2022) On February 1st, 2022, my 86 year old mother ascended from her body which was slowly being brutalized by ALS. My beautiful and strong mother fought against this disease until one day I said to her, "Mom, please stop fighting. We will be OK. You are suffering way too much." About a week later, she broke free of this awful, awful disease. My heart is broken because I watched my mother suffer and I witnessed her health decline over the past 2 years. From day to day, week to week, and month to month, basic functions that we take for granted were stripped from her such as speaking, smiling, holding things with her hands, extending her fingers, eating, walking, getting dressed, etc. During her last days she was only able to respond by blinking. The only thing that ALS didn't strip her of was her mind. My Mom was aware of everything that was happening to her until her last moments. Knowing that my Mom is no longer trapped in her body and suffering with discomfort, pain, and lack of her independence, helps to bring me peace. She is free. ☹️
Please pray for my family while we get through this difficult time.
+fotografie

5. (10. leden 2022) My mom is 86 with ALS. Everyone automatically assumes that because she can't help herself at all, that she doesn't know what's going on. Why is that? My mother's memory is better than mine right now.

6. (31. prosinec 2021) My mother's health has declined over the past 2 weeks, even since Christmas day. She is now down to blinking to respond. She is barely able to nod or shake her head or use her board to spell words. This disease is the worst! If it were a physical thing, I'd smash it to pieces.

7. (16. říjen 2021) What would you do?
A consistent home health aide is difficult to find. We have a consistent one for the most part, but after she changes my mom's diaper, she spends the rest of the time on her phone. My mom said she asked her all week to do her hair, but she didn't do it. She's here for 4 hours. She doesn't do jobs that are less than 6 hours, and she said the only reason that she took this assignment is because it's my mom. (She covered for another aide a while ago, so she was familiar). She hasn't changed my mom's linen either. I end up doing it. I want to say something to her and to the agency, but I'm afraid we'll get someone who shows up twice a week instead of 5 days per week.
Should I let it be, or should I say something?

8. (14. září 2021) My mom had slippers on and would not allow women to assist her with standing up. She would always be in a seated position with her legs spread out in front of her. Today we put sneakers on her and she stood right up. Now that my husband is home, she's claiming that she can't stand, and she wants him to help her. This woman is trying my patience. Lol!

9. (31. srpen 2021) This was my mom in April 2020. Today, she cannot walk. Her last time walking unassisted was July 18th, 2021 when she was admitted in the hospital for breathing issues. She spent 2 weeks in the hospital in bed. She went to rehab for 20 days and was walking with assistance, and they even had her going up and down the stairs also with assistance. She came home on Aug 17th. She doesn't trust that I won't make her fall, so she won't try to walk. 🙄 She'll never walk again. It's so crazy how this disease takes away a piece of you on a monthly or weekly basis. +video

10. (20. srpen 2021) So the latest on my mom.... A week after her g-tube was pulled out by the Aide at rehab, she was discharged home. Two days later, she's back in the ER, because the foley catheter balloon went into her intestines. She is now admitted to the hospital to get the catheter replaced with a g-tube. This is what we've been fighting for since it was pulled out.

UPDATE: The g-tube has been replaced, and my mom is doing well. I'm not sure of when she'll be discharged though. 🙄🙄

11. (14. srpen 2021) My mom is in rehab. She got her g-tube placed about 3 weeks ago. On Sunday, an Aide that was tending to her, pulled out her g-tube. Now she has a foley catheter in its place, and they won't replace the g-tube at the facility because it's less than 3 months old. I'm so pissed! The Aide claims when she pulled my Mom's gown back, the g-tube was laying there. My mom said the Aide did it, and said she was rough with her. My mom can't use her hands, so she didn't do it. Everyone else there agrees. She also has her faculties about her and knows what's going on. They are discharging her next week with this catheter instead. I'm not happy about this at all!

12. (3. srpen 2021) G-tube question: Isn't the tube supposed to be clear of any liquids when feeding is complete? My mom's tube has water sitting in there, like it didn't go all the way down.

UPDATE: I watched my Mom's nurse plunge the food through the tube because it wouldn't go down. This doesn't seem right! Please tell me I'm wrong.

13. (26. červenec 2021) My mom is 86 and was diagnosed last May. Last Sunday she was rushed to the hospital due to her weezing. Since then she had a peg tube placed. She passed the barien swallow test, and was given the option to eat orally or via the tube. The next day she choked when fed orally, so she now has to be fed only by tube. Now she chokes even on her saliva, and goes into respiratory distress. Today she choked 3 times, and I was there for one episode. It was bad. I'm remaining positive, but realistically thinking, I don't know if she'll leave the hospital alive. She's supposed to go to rehab today, but I don't know. If she does, I don't think she'll come home. I've done everything that I can for her at this point.



14. (19. červenec 2021) Do PALS generally develop asthma? My mom was rushed to the hospital because she was weezing uncontrollably. The doctor said she has asthma. My mom is 86 and never had it before.

15. (20. květen 2021) A cup to help your PALS, to help prevent choking. The Provale Cup is a Limited Flow Cup for the delivery of thin liquids.
https://www.amazon.com/dp/B00CZ3GGHG/ref=cm_sw_r_cp_awdb_imm_2DW1076CTW62HXX46KQT?_encoding=UTF8&psc=1&fbclid=IwAR2Z7odsDLdCbff-7_tyCvv6VzGSNizBAdncTUWWTiWwXMeG9_r_EQz4yFw

A curved

spoon to help your PALS. -

https://www.amazon.com/dp/B07KLZVM7K/ref=cm_sw_r_cp_awdb_imm_K4GADMMQH01VHXVZX5PZ?_encoding=UTF8&psc=1&fbclid=IwAR1Aun7aqWnOGk_6iOMNqIV-XHa3M_a2RvWI999yxfbKS9R8L68pj_3vGNU

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text	Výpověď	Vděčnost za existenci skupiny a poskytnuté rady, podporu	241
Text	Výpověď	Předání osobních informací	84
Text	Výpověď	Příznaky	118

Text a multimédia	Výpověď	Stárnutí a umírání	576
Text	Kombinace	Péče o zdraví, prevence	185
Text	Výpověď	Změna zdravotního stavu pacienta	133
Text	Kombinace	Výběr pečovatелů a zdravotnických zařízení	19
Text	Výpověď	Zábava	18

Text a multimédia	Výpověď	Změna zdravotního stavu pacienta	112
Text	Výpověď	Změna zdravotního stavu pacienta	41
Text	Výpověď	Stravování	61
Text	Dotaz	Stravování	3
Text	Výpověď	Změna zdravotního stavu pacienta	40

Text	Dotaz	Změna zdravotního stavu pacienta	19
Text a odkaz	Doporučení	Pomůcky	2

Průměr reakcí: 110,1
Průměr komentářů: 38,66667
Součet reakcí: 1652
Součet komentářů: 580

Počet komentářů

33

24

9

212

55

29

54

5

27

10

64

20

12

26

0

Pečovatel 4

Žena

Počet příspěvků:

14

Přispívá:

Pečovatel (manželka)

Příspěvky:

1. (10. březen 2022) Did any of your Pals use this wedge or something similar? I wonder if it is comfy *+fotografie*

2. (23. únor 2022) Hey everyone, its 430am and I am on and off sleep with F30 mask problem with lower lip of my pals escaping the mask. Apparently it only comes as medium in size and we need a chin strap to correct this. Is this true? What are your experiences? any tips? My pals hubby is getting fed up with all the changes . please help. Thank you in advance.

3. (30. leden 2022) My husband was crying last night. He said he wants to reach 80 years of age. He is 45. I didn't know what to say. It's so heartbreaking. It's so hard.

4. (29. leden 2022) Hello, we are having our initial consultation with a Consultant who will assess my husband Pals for Cannabis treatment for anxiety tomorrow, I am a bit lost. Can anybody give me a clue to what I can ask? He is experiencing anxiety attack almost every night, some mild and a few major ones that lasts for more than hour. I find that when I massage him he feels better after, did anybody start with cannabis oil? Is it as effective as peg introduced? What are your experiences please.? Thank you in advance-

5. (25. leden 2022) Help!!! CPAP mask is marking my hubby's cute nose. What do you guys use please???? Thank you in advance. *+fotografie*

6. (23. leden 2022) When I have a back pain, or a bruise or I couldn't go out when the sun is shining or if I miss my husband's voice and his laugh or even the silly discussions we used to have, I remind myself, my husband is his best self today and I should be thankful. I can hug him, hold his hands, he can write words for me then I make them into sentences until I get what he wants 😊, he can hold my hands when he can see I am upset, he sleeps better now than few weeks ago because of finally trying his CPAP machine at night. He gets anxious but he looks at me and after a few minutes I can see him getting better. Its one horrible day at a time now for us, but we have lots of moments where we smile at each other and I hope he doesn't feel alone in this, that he has me always.

I was overthinking last night about the future his future battles still to come and It really affected me.

And I go back to this group and lots of people are on the same boat as us, helping each other and making jokes and living, fighting this disease.

I just want to say to whoever reads this, you are AMAZING.

My husband too...having to give me a smile every morning and precious moments ☺ that lasts forever xxx

Love to all, and have a great day +fotografie

7. (9. leden 2022) Hello, please can I ask what do you use to keep your head up in a good position. I have bought a lot of neck braces from just like chin rest, discreet ones to a supplied by hospital bulky neck brace. My Pals husband rejects them as he feels like choking and don't like anything on his neck . I also bought a travel pillow or I use a rolled towel, he doesn't mind that but it doesn't stay in place for the whole night. I am out of ideas and it really bothers me to see his head down to his chest and complains that his neck is sore. What do you guys do?

Thank you in advance x

8. (7. leden 2022) My husband giving me Love ♡. Have a lovely morning Everybody from us here in Edinburgh Scotland. +fotografie

9. (6. leden 2022) Hello, did anybody used a chiropractor and or acupuncture and felt the benefits especially in the neck area muscle control and pain with neck strain?

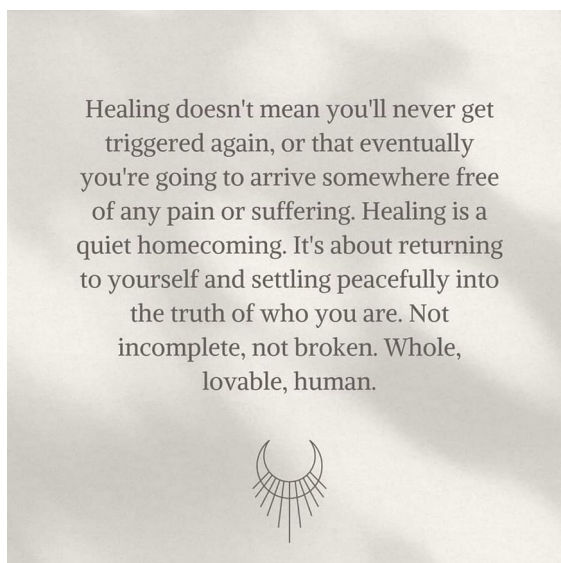
10. (21. únor 2022)

Table 1. Properties of marijuana applicable to ALS symptom management	
ALS symptom	Marijuana effect
Pain	Nonopioid analgesia and anti-inflammatory
Spasticity	Muscle relaxant
Wasting	Appetite stimulant
Dyspnea	Bronchodilation
Drooling	Dry mouth
Depression	Euphoria
Dysautonomia	Vasodilation
Neuronal oxidation	Neuroprotective antioxidant

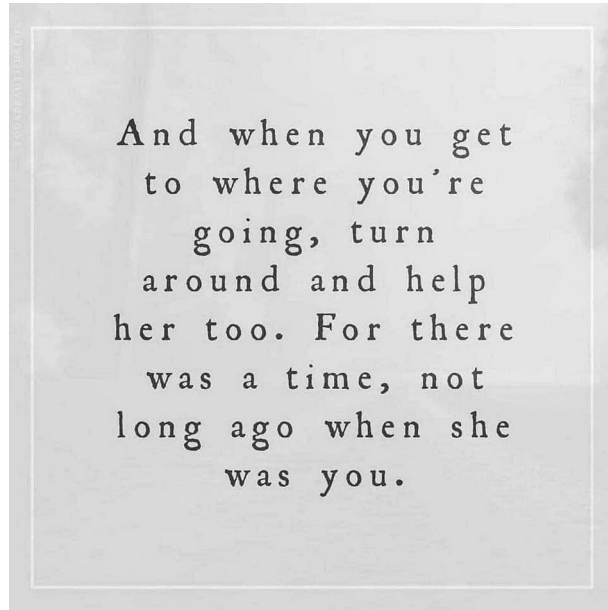
11. (4. únor 2022) Good day to all



12. (17. leden 2022)



13. (17. leden 2022)



14. (15. leden 2022)

Some days you will
The Cool Shady Tree
be the light for others
and some days you
will need some light
from them.
As long as there is
light there is hope
and there is a way

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text a multimédia	Dotaz	Pomůcky	3
Text	Kombinace	Pomůcky	2
Text	Výpověď	Strach z budoucnosti	675
Text	Kombinace	Užívání léků	7
Text a multimédia	Dotaz	Pomůcky	40

Text a multimédia	Výpověď	Myšlenky, psychologie	524
-------------------	---------	-----------------------	-----

Text	Kombinace	Pomůcky	10
------	-----------	---------	----

Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	882
-------------------	---------------------	------------------------------------	-----

Text	Dotaz	Vyhledání pomoci	1
------	-------	------------------	---

Pouze multimédia	Doporučení	Příznaky	47
------------------	------------	----------	----

Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	209
------------------	---------------------	------------------------------------	-----

Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	58
------------------	---------------------	------------------------------------	----

Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	176
------------------	---------------------	------------------------------------	-----

Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	242
------------------	---------------------	------------------------------------	-----

Průměr reakcí: 205,4
Průměr komentářů: 43,57143
Součet reakcí: 2876
Součet komentářů: 610

Počet komentářů

10

33

138

58

87

128

25

91

5

14

6

1

4

10

Pečovatel 5

Žena

Počet příspěvků:

18

Přispívá:

Pečovatel (dcera)

Příspěvky:

1. (9. březen 2022) With hurricane season approaching I am looking for some backup battery alternatives for my mom's trilogy machine. Any suggestions? Paying \$14,000 for a generator is not feasible.

2. (25. listopad 2021) When do you know when to put someone on hospice? What are questions to ask? What are things I should know?

3. (10. listopad 2021) My mom has excessive burping. What can i do? Is this normal?

4. (12. červenec 2021) What is everyone using as a battery backup for the Trilogy machine. I am trying to prepare for hurricane season. Thanks.

5. (15. červen 2021) My mom has been feeling nauseous all day. She says she has to vomit but its only saliva coming up. Any suggestions? I don't know wgat to do 😞

6. (25. duben 2021) My mom suddenly needs her trilogy more often. Is this normal?

7. (27. leden 2021) Is there anything thats works fast for constipation? Sorry dont want to offend anyone 😞

8. (15. listopad 2020) Any ideas how to get rid of a bedsore?

9. (12. říjen 2020) Has anyone used this to prevent pressure sores? Does it work?



10. (4. září 2020) My mom said she has a sharp pain on her left side. Does anyone else experience these type of pains?

11. (4. září 2020) Does anyone take blood thinners to prevent blood clots? The doctor said my mom needs them since she is not active.

12. (26. srpen 2020) Better Days are Coming Pal and Cals. This song has helped me get through many days! Wanted to share. +video

13. (26. srpen 2020) Am I the only one that has a hard time trying to get family or friends to understand my Pals condition? I feel like I am on repeat. I can't, I ain't, and I won't rip and run the streets with you. All my time and energy is used to care for my Pals. I dont mind taking care of my Pals. I wish I could help others take care of their Pals. But what is annoying is explaining to family and friends the same thing over and over. I am busy. My focus is my mom! That's it! Geez 🙄

14. (25. srpen 2020) I remember one day I was pulling my mom (Pals)back on the bed and she was screaming because she thought she was going to fall. So I started screaming at her for screaming and she started crying. Of all of the 42 years I have been on this earth I have NEVER seen or heard my mom cry. She is the strongest person I know! From that moment my #1 goal was to make sure my mom is happy and taken care of everyday. This is the purpose God has given me at this moment in my life. He has provided and will continue to provide whatever we need. No job or material things can ever replace the time I have here on this earth with my mom. To all the caregivers stay strong and push through. Remember to take care of yourself also. Set time each day or week to do something for yourself and remember you are not alone. We are all in this together 😊

15. (25. srpen 2020) Pals and Cals when you feel discouraged and alone keep going ♥♥♥♥♥



16. (22. srpen 2020) Does medicare cover the cost of wheelchairs?

17. (28. červenec 2020) My mom was thinking about participating in a clinical trial? Has anyone tried this? What are your thoughts?

18. (27. červenec 2020) Hello. Thank you for allowing me to join. My mom was diagnosed in Jan/ February. Any suggestions on how to prevent bed sores?

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text	Dotaz	Bezpečnostní opatření	1
Text	Dotaz	Vyhledání pomoci	4
Text	Kombinace	Péče o zdraví, prevence	0
Text	Dotaz	Bezpečnostní opatření	0
Text	Kombinace	Změna zdravotního stavu pacienta	0
Text	Dotaz	Změna zdravotního stavu pacienta	1
Text	Dotaz	Péče o zdraví, prevence	20
Text	Dotaz	Pomůcky	7

Text a multimédia	Dotaz	Pomůcky	2
-------------------	-------	---------	---

Text	Dotaz	Změna zdravotního stavu pacienta	0
------	-------	----------------------------------	---

Text	Dotaz	Užívání léků	4
------	-------	--------------	---

Text a multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	2
-------------------	---------------------	------------------------------------	---

Text	Výpověď	Negativní pocity pečovatele	57
------	---------	-----------------------------	----

Text	Výpověď	Myšlenky, psychologie	181
Pouze multimédia	Motivace a pobavení	Motivování ostatních členů skupiny	53
Text	Dotaz	Pomůcky	4
Text	Dotaz	Kvalita zdravotnických služeb	6
Text	Kombinace	Předání osobních informací	2

Průměr reakcí: 19,1
Průměr komentářů: 20,33333
Součet reakcí: 344
Součet komentářů: 366

Počet komentářů

10

27

10

19

9

10

77

60

7

2

24

0

24

34

0

31

10

12

Pečovatel 6

Žena

Počet příspěvků:

31

Přispívá:

Pečovatel (dcera)

Příspěvky:

1. (4. březen 2022) Dad can not hold his paperback books really anymore. Any ideas to help. He does not want them on a kindle he wants the paperback ones they are old westerns Also trouble holding small things to get a drink we use straws and hone his drinks but would sippy cup be easier

2. (2. března 2022) Dad is on the Bipap 24/7 he doesn't even want to take off to eat. He eats a pudding snack and that's about it. This disease is so brutal ☹️

3. (10. únor 2022) Anyone else PALS have upset tummy's for weeks in end? He hardly eats anymore. Nothing helps. 😞

4. (10. únor 2022) My dads been having pain in his tummy for days. The nurse had no clue. He potty's once a day when we go over to transfer. He feels horrible could it be something else? Anyone else have tummy trouble ??

5. (4. únor 2022) My dad says nothing taste good and seems like it has no flavor. Has anyone else experienced this perhaps?

6. (28. leden 2022) They dropped off the cough assist machine. But no one knew how to tell us to use it. The person that was suppose to show us is sick and could not show us. Dad tried it and started coughing so we took it off 😞 anything we need to know? They said when someone is well they will send out.

7. (26. leden 2022) They delivered the suction machine but I was not here. He says it's not working. Is there a trick to this thing? He was putting it in his nose I though it was for back of throat.

8. (25. leden 2022) What can you get to help suck flem out of Pals throat?

9. (21. leden 2022) Dad just started oxygen but it makes his throat hurt. Is this normal? He is on level 2

10. (20. leden 2022) Dads heart rate is 114 doctors we called they said they would get him monitor. how can I help get it down? Think one of his doctors he spoke to today upset him and she was extreemly hateful to him. I've been massaging him any other tips.

11. (10. leden 2022) Dad is horse today and said having trouble breathing. 🤔😞 is this because he is losing voice? He has an appointment in May to see pulmary specialist. That is forever wait 😞

12. (7. leden 2022) Dad has been drinking protein shakes like boost but it's giving him gas. Is there any other high protein recommendations? He is only able to drink right now.

13. (7. ledna 2022) Can you get bed rails without having a hospital bed. We are getting conflicting answers from all the different therapist that come over.

14. (5. leden 2022) Help....dad is getting harder and harder to transfer as he declines.. the PT can't even get him on potty potty with the hoyer🤔😞any ideas how to make using the potty not so hard. I'm about to cry listening to him.

15. (1. leden 2022) We can not find anyone for lift help. The hoyer will not work on the carpet and VA has not pulled it up yet. Checked several places and no one does lift help. Any help appreciated. It's getting harder and harder to lift him.

16. (22. prosinec 2021) There is no off button for hoyer
It's a hoyer advance 340
Does not work on our rugs 😞but need it off

17. (8. prosinec 2021) My dad can't sleep and said he is in so much pain in his legs anything and he has to pee every hour is this normal ?

18. (23. listopad 2021) Going to pick up hoyer for parents but my sister mentioned the low bed and thick carpet may hinder using it. At least in that room. Ideas?? Thoughts?

19. (11. listopad 2021) Has anything helped your PALS with swollen ankles. Compression socks have not helped very much.

20. (10. listopad 2021) My parents went to the doctor and they were no help! They asked about a hoyer to lift him and they dismissed it. Said it was big and bulky. My mom can not lift him. Don't know what to do. We need something skinny to get through doors. The transport will not fit the wheelchair will not fit 😞😞😞no construction on there bath room is even close said it's months away

21. (7. listopad 2021) What is the easiest way to travel? My dad wanted to make it to Oregon so he will have been to all 50 states. Now that he is in a wheelchair and things are moving faster than we thought.

22. (31. říjen 2021) I tried it first to make sure he won't fall. This is not working at all 😞😞 How do you get from wheelchair to car? +fotografie

23. (31. říjen 2021) My dad keeps falling. When he tries to transfer from certain places. He has hurt his ankles and knees. I don't know what to do to help my parents 😞 usually transfer chair to potty 😞 he can't fit in the rooms of the house with the wheelchair so has to use the walker

24. (18. říjen 2021) Updated

Someone from this group reached out and gave me a cell number to the chapter and I was able to talk to someone. They are not at the office right now due to Covid. I have reached out numerous times to the ALS chapter to get help and no one calls me back ever. Is this typical?

25. (15. říjen 2021) My dad wants to take my son hunting one last time. He knows he can't be in the woods with him so he will stay back at the vehicle. Please give me pointers on how to get him in the truck with no use of his legs. His friend is taking my dad and son. Any ideas are appreciated

26. (8. říjen 2021) My dad is having a hard time taking a shower and is in a wheelchair my mom is little and there is a small lip on the shower. It's a slipper on the shower is there any pointers till they can get the shower redone on how to transfer in the shower

27. (2. říjen 2021) Have an appointment with 2nd MD tomorrow what questions should we ask?

28. (2. říjen 2021) My daddy's legs no longer work but he tries so hard to keep just using the walker. He lifts weights with his arms as he still has strength in them. Question is it hurting him pushing himself. He's afraid if he stops trying that it will go faster. He worked out 2 hours everyday for 30 plus years???

29. (30. říjen 2021) They just put my dad on Rilutek but none of the pharmacies have it. They are trying to get it anyone else have this issue? What do you think of this drug and why can't they seem to get it.

30. (29. září 2021) My dad has always had trouble sleeping but since the diagnosis neither of my parents can sleep. What have you seen help?

31. (21.žáří 2021) My dad goes to his first appointment on the 28th after getting the diagnoses over the phone. What should we expect and any questions that need to be asked we might not have thought of? I saw there are different types. How do they no if yours is slow or a faster progression?
Thanks for any advice.

Zařazení dle typu	Zařazení dle druhu obsahu	Zařazení dle ADLs	Počet reakcí
Text	Kombinace	Pomůcky	20
Text	Výpověď	Stravování	115
Text	Dotaz	Stravování	16
Text	Kombinace	Příznaky	12
Text	Kombinace	Příznaky	18
Text	Kombinace	Pomůcky	8
Text	Kombinace	Pomůcky	13
Text	Dotaz	Pomůcky	11
Text	Kombinace	Pomůcky	5
Text	Kombinace	Péče o zdraví, prevence	16

Text	Kombinace	Změna zdravotního stavu pacienta	10
Text	Kombinace	Stravování	5
Text	Dotaz	Pomůcky	8
Text	Kombinace	Pohyb a přemístování (v domácnosti)	14
Text	Kombinace	Pohyb a přemístování (v domácnosti)	7
Text	Výpověď	Pohyb a přemístování (v domácnosti)	1
Text	Dotaz	Nespavost a poruchy nočního chování	6
Text	Kombinace	Pomůcky	2
Text	Kombinace	Péče o zdraví, prevence	2
Text	Výpověď	Pomůcky	31
Text	Kombinace	Přemístování (mimo domácnost)	1

Text a multimédia	Dotaz	Přemístování (mimo domácnost)	22
Text	Výpověď	Změna zdravotního stavu pacienta	3
Text	Kombinace	Výběr pečovatelů a zdravotnických zařízení	6
Text	Kombinace	Přemístování (mimo domácnost)	6
Text	Kombinace	Koupání a sprchování	6
Text	Dotaz	Návštěvy lékaře, prohlídky, operace	3
Text	Kombinace	Pohyb a přemístování (v domácnosti)	26
Text	Dotaz	Užívání léků	0
Text	Dotaz	Nespavost a poruchy nočního chování	1

Text

Kombinace

Návštěvy lékaře,
prohlídky, operace

12

Průměr reakcí: 13,1
Průměr komentářů: 32,64516
Součet reakcí: 406
Součet komentářů: 1012

Počet komentářů

15

34

48

39

23

45

46

21

8

40

19

15

43

79

48

3

23

16

15

91

13

54

28

33

5

51

19

46

31

5

