

2018 Largest fatigue survey results



*The world's largest social network for cancer
patients and caregivers*

May 9th, 2018

Disclaimer

The survey was conceived and implemented by Belong.life on a pro bono basis, no fees were paid to Belong.life.

The survey results presented in this report are not statistically valid and should not be considered as an accurate reflection of the opinions of the respondents. Neither the questions nor the survey methodologies conform to standard practices. Participant responses have not been verified. This survey is for information purposes only. Due to sample size, results should be seen as issues for further discussion, not complete representations. We assert that any business or investment decisions should not be made solely based on the information presented in the survey.

Although care has been taken to ensure complete and accurate survey results, recipients of this survey accept the possibility of unintended errors or omissions. The provided data will be summarized and anonymized and in no event will include personal information.

About Belong

Belong.Life is the world's largest social network for cancer patients and caregivers. Belong is a free patient navigation app that gives voice to cancer patients and their support network to explore and better manage their treatment journey and improve quality of life. The belong app and community enables our "Belongers" to connect with top physicians, advocates, providers and other patients undergoing similar treatment, empowering them to share information, learn, consult, manage and overcome mutual challenges.

About Fatigue

Fatigue is a common symptom reported by cancer patients and which in high levels affects their quality of life, emotional, psychological and lifestyle.

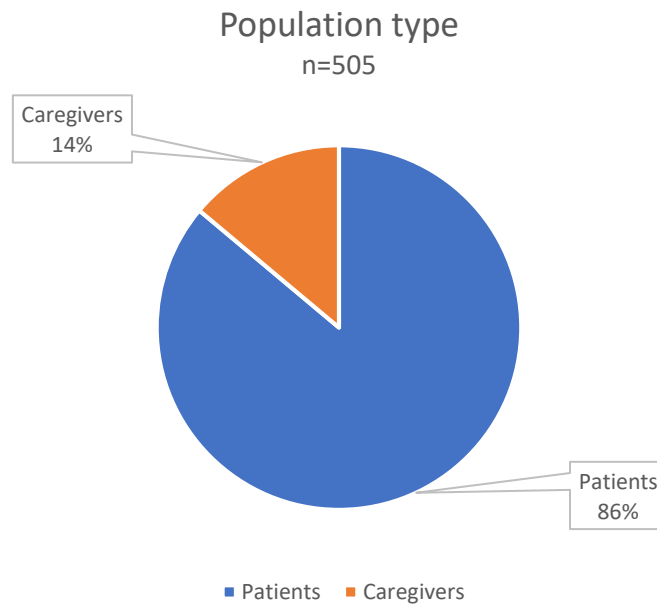
Survey

A real-world data survey was designed to evaluate, from the patients' perspective, the fatigue effect on their treatment, as well as their emotional and physical state.

A survey was created in a digital format with 13 questions. The survey was sent to a random group of patients that are members in the Belong community. 505 patients completed the survey anonymously. Here we report the results of the survey followed by a mathematic model and machine learning analysis that revealed correlations hidden from the human eye.

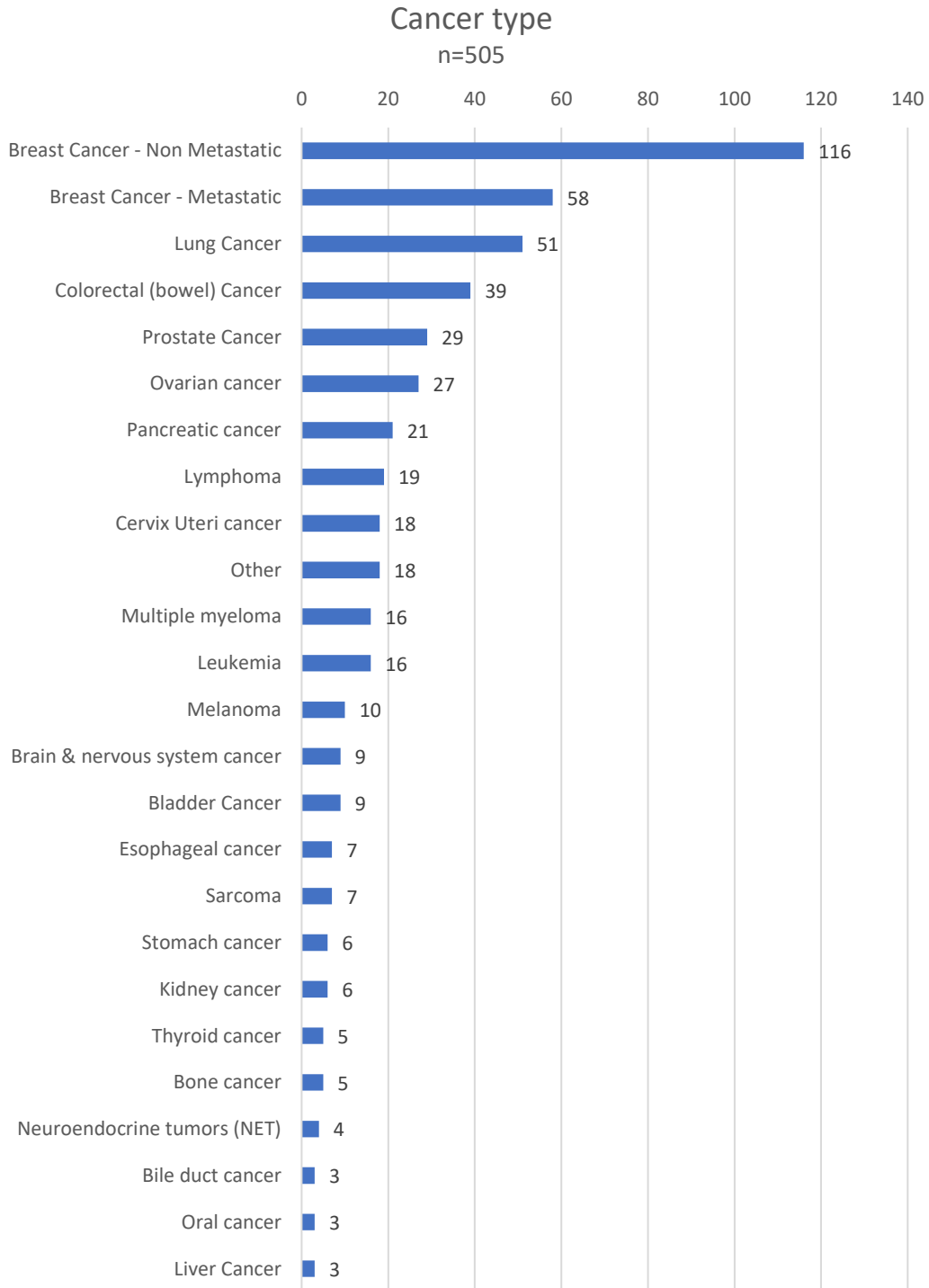
Survey responses

Question #1: I am a...



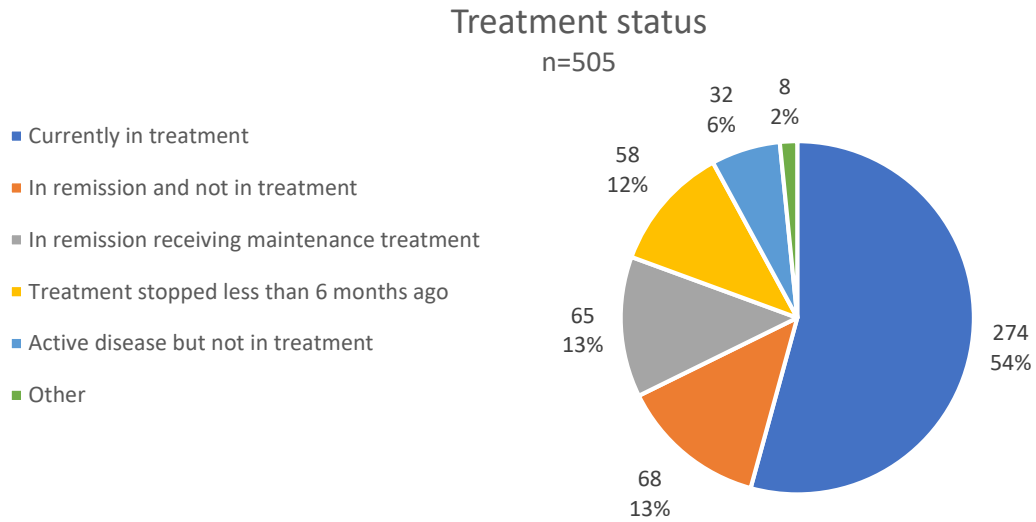
86% of the users that completed the survey were patients and 14% were caregivers.

Question #2: What type of cancer are you dealing with?



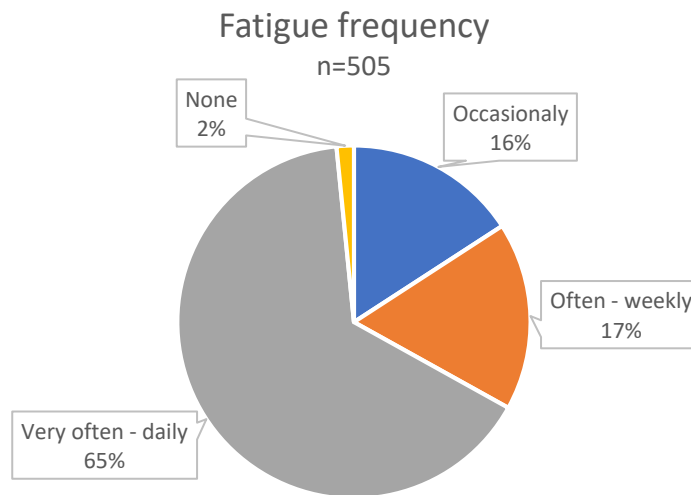
Users dealing with 25 different types of cancer completed the survey and the three leading cancer types were breast, lung and colorectal cancer.

Question #3: What is your current treatment status?



Belong users completing the survey were at different stages of their journey and 54% of them were in treatment for active disease at the time of survey completion

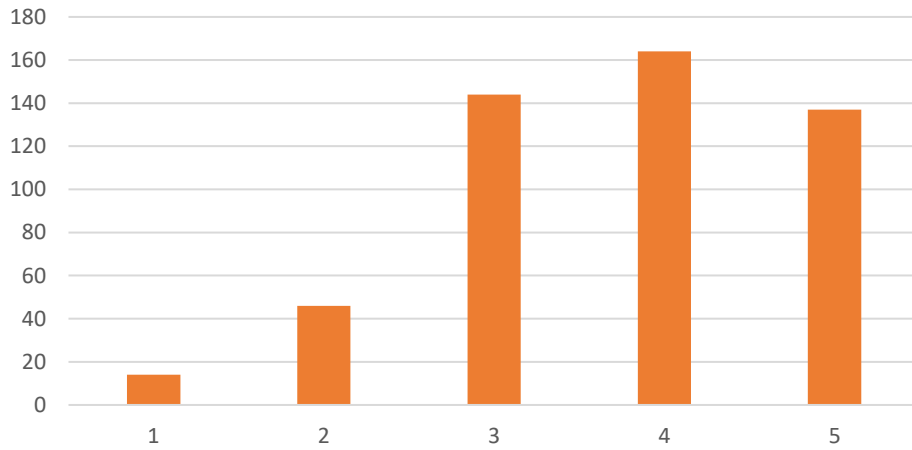
Question #4: When you experience fatigue, how often do you have it?



The majority of users (65%) reported they felt fatigue on a daily basis

Question #5: How does fatigue affect you physically? (Daily activity, physical performance, mobility, pain etc.)

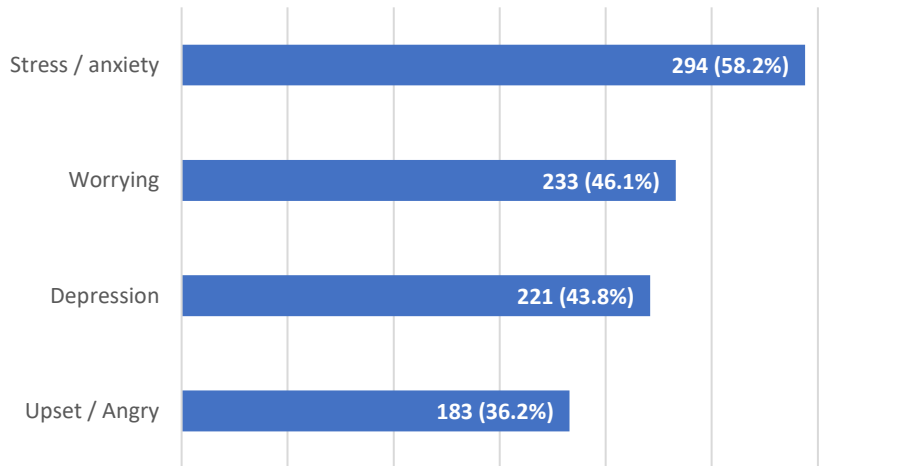
The physical impact of fatigue
(1-Not at all, 5-Very much)
n=505



The majority of the patients (59.6%) claim that fatigue has a big physical impact (≥ 4) on their life

Question #6: Which emotional effects did you experience as a result of fatigue? (multiple choice)

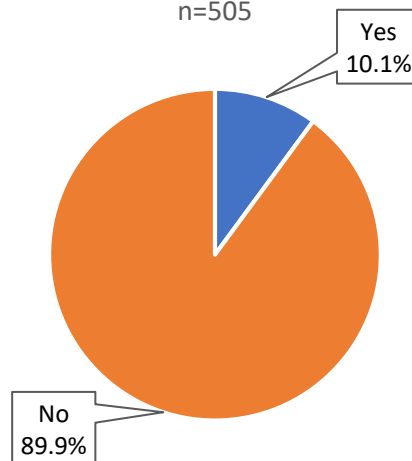
The emotional effect of fatigue
n=505



Users reported significant emotional effects resulting from fatigue, with stress/anxiety affecting 58% of the patients.

Question #7: Have you ever stopped, delayed or changed your treatment due to fatigue?

Treatment adherence - stopping or delaying treatment
n=505



10% of the users completing this survey experienced adherence problems with their treatment regimen (10.1%)

Question #8: If YES, please elaborate more on the reasons that led you to stop/delay or change a treatment due to fatigue

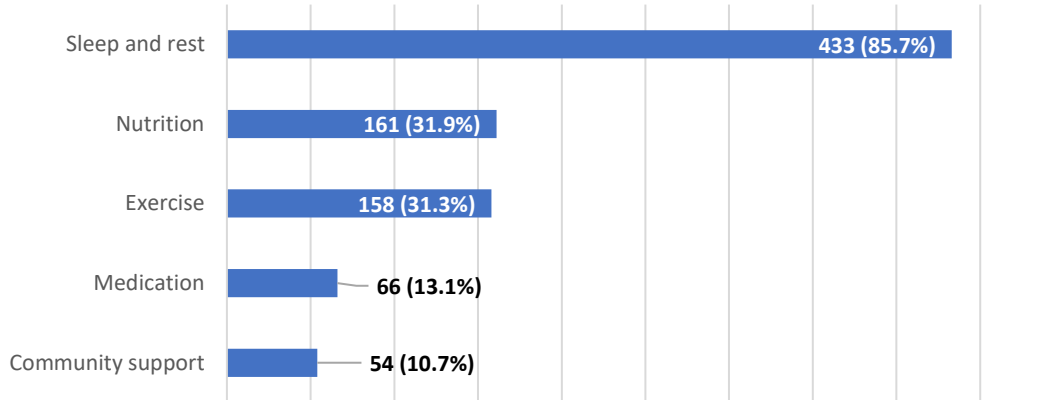
These are some selected answers provided by the survey responders:

- Too tired to go
- My body was just so tired and achy from the treatment along with nausea
- My cancer is incurable so quality of life led me to seek treatments other than chemo.
- Dr about to stop treatment now temp. For body to rest then start again. I'm not sure I want to go thru that nor do I want to change to different med. The meds all have their own side effects. I have concluded that cancer kills whereas side effects just drag on an on....
- Couldn't make it physically to another treatment
- Dr is allowing me to have 3 months on, 3 months off this is really helping me get through this
- Depression and couldn't see the point
- Joint pain which lead to fatigue
- Stopped treatment as was too tired.
- No strength to have treatment
- Needed more time to recover after chemo/radiation before starting hormone blocker med.
- Energy level just too low to even push through. Then I cycle with frustration. The tension then produces headaches and muscle pain which then causes more fatigue. Often after a good energy day, or period of day, I fallout with fatigue that shuts me down. Taking tea and supplements to help.
- Was hard to be an employee, wife and mother because of the treatment related fatigue, took a chemo break

Question #9: What are the top two methods you found as most helpful to overcome your fatigue?

Methods that helped alleviate fatigue

n=505



Sleep and rest were the top methods that helped patients in overcoming fatigue (85.7%) followed by nutrition (31.9%)

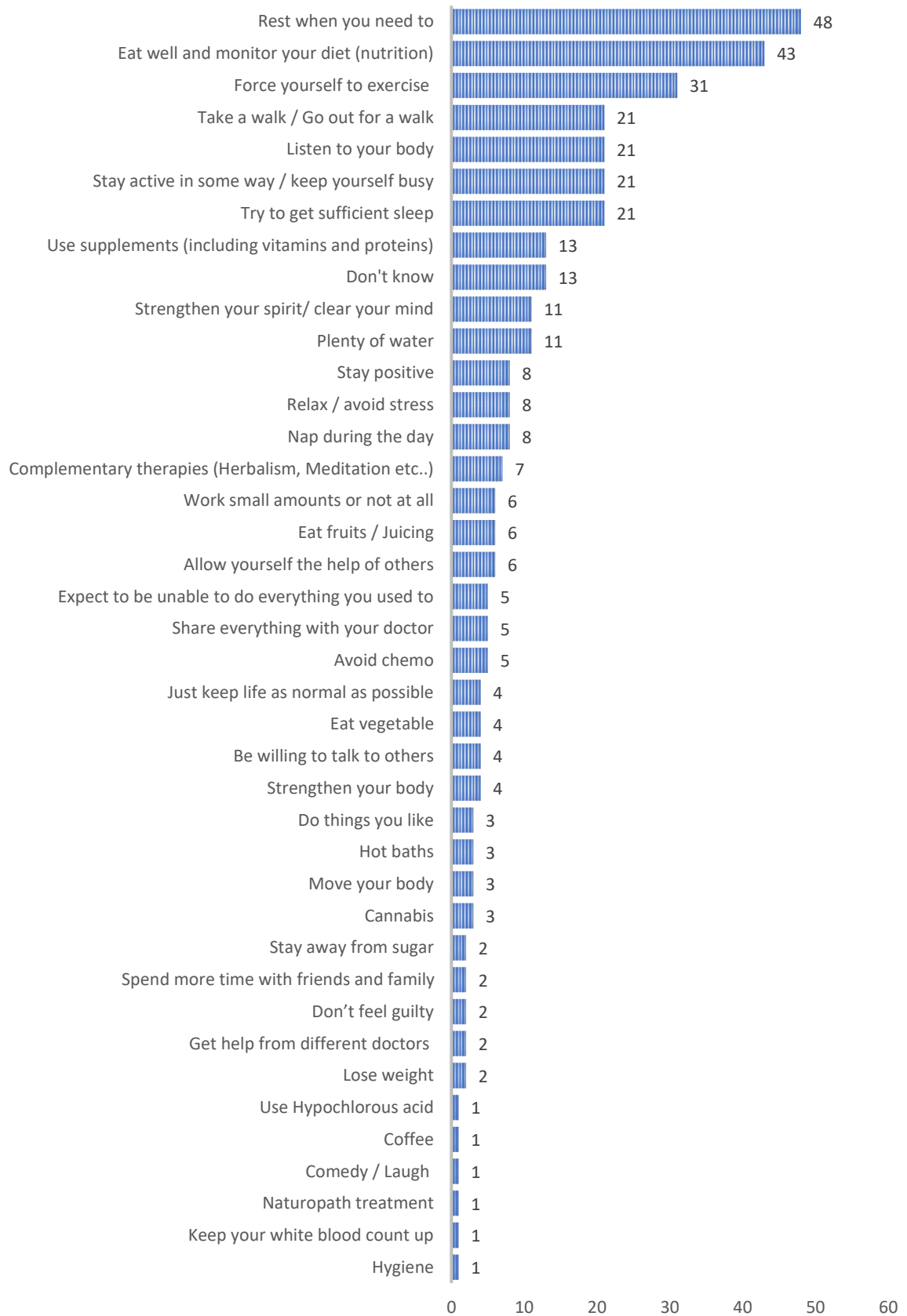
Question #10: Please elaborate: If you had tips for yourself to avoid fatigue when starting the treatment journey, what would they be?

Users provided dozens of tips. We aggregated them as some tips overlap but a full and detailed list of tips can be found in the appendix

Common words in the responses:

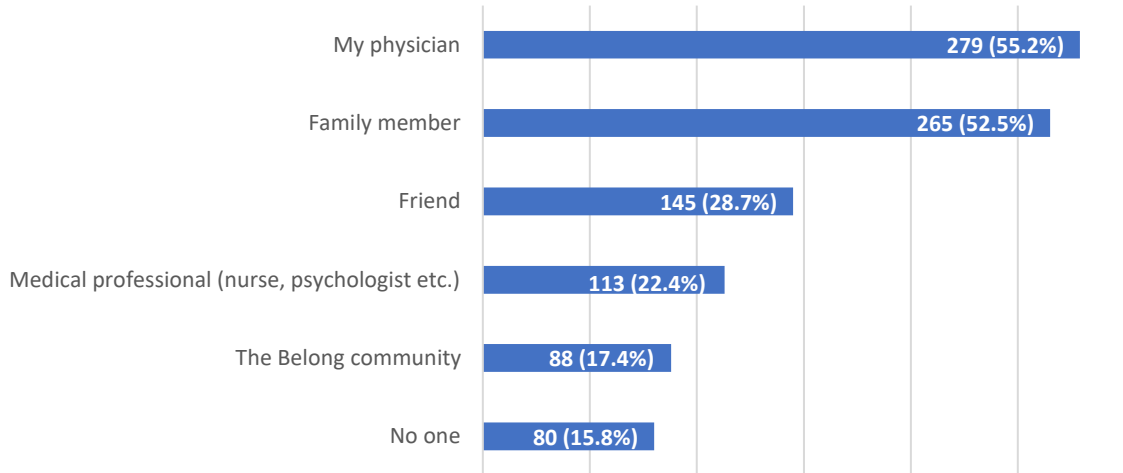


Aggregation of tips



Question #11: Who do you approach to discuss your challenges with fatigue? (check all that apply)

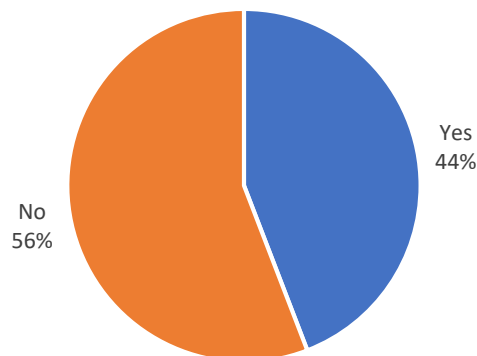
Discussing fatigue with:
(n=505)



Patients discussed their challenges with fatigue mainly with their physician (55.2%) and family members (52.5%)

Question #12: Do you feel that Belong's physicians, community, informative content or tips have been helpful to you in coping with fatigue?

Did Belong help you in coping with fatigue?
n=505



44% of users feel that Belong's platform helped them cope with fatigue

Question #13: If YES, please elaborate.

[See appendix]

Unveiling hidden patterns using Machine Learning

Belong's Machine learning algorithms are utilized to find undetectable correlations between parameters based on mathematical models and create predictive models.

These are 2 examples of the many findings from Belong Machine Learning decision tree models based on the responses to this survey:

Predicting depression among Cervix uteri and Lung cancer patients:

IF

↳ Patient has Cervix uteri cancer and experienced fatigue

AND

↳ Patient report fatigue with a physical affect of ≥ 4 (from a scale of 1-5)

THEN

↳ There is a 77% chance they will experience depression.

IF

↳ Patient has Lung cancer and experienced fatigue

AND

IF

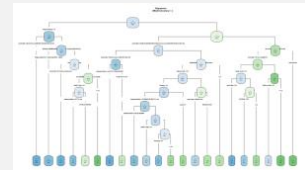
↳ Patient report Stress

THEN

↳ There is a 73.6% chance they will experience depression.

ELSE (Not reporting stress)

↳ There is a 52.9% chance they will experience depression.



Appendix

Question #13: If YES, please elaborate. (Do you feel that Belong's physicians, community, informative content or tips have been helpful to you in coping with fatigue?)

(Selected responses)

- I read issues that I am also being challenged with.
- Knowing how others are managing and coping in their paths is helpful and mitigates the isolation and lack of understanding from people who are not going through these experiences
- Offers options
- I'm the patients Daughter in law. She lives in Ontario I live in Alberta. Through reading Belong we are trying many different things that have been helpful to her and have appreciated other people's tips and advice, Thank you very much 😊🙏
- I ask advice or what I can do, I feel that are my friends
- They gave me ideas such as oils or vitamins.
- I think the sharing helps everybody
- It helps to know others feel the same
- When I ask a question I get a fast response of what to do
- I like knowing I can ask advice from the community
- Having to read about how we stay positive and believe in ourselves.
- So much info on this site. Everyone us always trying to help with personal experiences. Ask a question...get an answer. Awesome
- I didn't realize how many different ideas the pink brothers and sisters had to cope with fatigue
- We can share our experience and learn to fight
- It's helpful to hear ideas from others
- others talk about it gives more insight on how to manage it
- Members told me why I was feeling fatigue
- By asking doctors and reading other comments
- A lot of my pink family have or are going through the same problems I'm experiencing and a lot of them have the answers or can tell me where to go on belong to find helpful information and tips.
- Helpful suggestions, encouragement that it is normal.
- All articles that are posted
- Especially to hear from the members of the lung cancer community what has worked for them.
- All Belong discussions help me remain positive and focussed.
- The tips from other belongers are helpful and encouraging
- Gives me different ideas on how to handle my fatigue
- There are so many ideas given by this community that would never have occurred otherwise.

- Very, love knowing am not alone
- We are all in this together
- They help you realize you're not alone
- Tips
- Suggestions from others
- Did not know about this at the time
- It's always good to have a support system
- Talking with other with the same cancer
- Other belongs members have given ideas as to move forward during my chemo/radiation and realize that the fatigue is temporary. Knowing that the tunnel has a light at the end helps you keep going.
- More information is always better.
- It's great reading everyone's input
- I haven't been on here very long, but it helps to know that you are not alone in this journey.
- I often look to see what others are doing that have helped them.
- There's always someone here to listen and give you any idea they may have done that helped them. Great understanding community of people that are going through this battle with you. They understand more than family and friends about what you're going through
- It helps to here what helps others and to know your not alone on this journey.
- It's good to know I am not the only one experiencing the side effects.
- I thought it was just me and my body was more sensitive to the medication
- Sometimes it just helps knowing that others are going through the same thing so that you don't think you're Doctor is just "telling" you what he thinks you want to hear. And sometimes what others try might help others in the same or similar situation.
- Just knowing that other have experienced this, handled it and carried on is inspirational.
- It helps to be in touch at any time with others who have gone through the same.
- I get myself busy engaging in a chat or just read what other members write and I forget about my fatigue.
- We have gotten some tips on nutrition
- Learned medication that contributes.

Question #10: Please elaborate: If you had tips for yourself to avoid fatigue when starting the treatment journey, what would they be?
(Selected responses)

List of selected tips:

- Stay active
- A healthy breakfast and a little walk
- Learning that it was ok to rest and nap
- Don't overextend myself
- Try and eat more.
- Drink lots of water, keep moving, nap at least once during the day, if needed, and stick to a sleep schedule.
- Naps light snacks. Lots of fruits and veggies. Lots of water. I completely stayed away from sugary snacks and soda. Hot bath before bed helped a lot
- Rest when you need to
- Try to keep extra stress minimal
- Getting on a low calorie high pristine diet as well as cardio has helped me lose weight and get in better shape has helped a ton with fatigue
- Listening to my body when it's tired
- Take time out for yourself as much as possible. If you can take off of work, do so.
- Eating healthy when you can and can tolerate healthy food. Mostly vegetables and fruits.
- Rest whenever you feel you need to. I listen to hypnosis apps to help me get to sleep. But get moving when you can, for double the benefit, get together with friends and walk, work out, dance, swim... Then rest again...
- Increase my protein earlier on treatment & allow myself the help of others.
- Stay as active as possible throughout. It's harder to get back into it after giving in to the fatigue.
- Just stay positive stay active
- Relax meditate
- Walking always help me especially the day before treatment. Yes medicine did help as well. Sometimes just sitting in a room and meditating let your brain empty yes it is hard but it helped no tv no phone no iPad just relax.
- Don't stop exercising.
- Started the intravenous vitamin c at the beginning
- Copaiba essential oil
- Short periods of activity time followed by short periods of rest time. Avoid stress. No big meals, several little healthy snacks each day. Have a pet that loves you. Surround yourself with people who care about you.
- Get plenty of rest and learn your limits
- Get lots of rest. Drink plenty of water
- Only do what I can & not push myself too far or I pay later for it.
- Eat lots of fruits and vegetable
- Rest when u can
- Try to rest on weekends nap when we can. Eat healthy and take vitamins.

- Changed my diet
- Exercise and spend more time with friends and family.
- Try to think of something else
- Plenty of sleep and walking prior to treatment
- Please get to a state where you can get the medical marijuana. It works with No side effects.
- Plenty of rest and watch tv to divert attention, count the blessings
- Get 8 hours of sleep a day
- Listen to your body.
- Continue to exercise as much as you can!
- Get more protein in
- Get up and move the body, do not just sit and find yourself with putting in any effort; this is open fight to overcome to finally be the person that we are. !!
- Rest rest rest!
- Do whatever it takes to get a good night's sleep
- Tell my doctor sooner
- Find helpers ahead of chemo treatment for grocery shopping, housecleaning, etc. Freeze meals ahead of time. Don't drive if you can avoid it. Too many meds, too drowsy.
- Nutrition
- Get proper rest and try to eat, protein worked best and also get out and move around the best possible way you can. I continued to work.
- Be really informed about your treatment side effects
- To concentrate on yourself go for a walk take time out try not to worry drink plenty of water
- Positive focused energy through meditation and rest followed by short spurts of walks out in the air
- Take short naps and eat lots of fruits and vegetables .
- Keep life as normal as possible . Stay busy, rest when needed. Exercise and do things to relax.
- Commented treatment as healthy as possible with moderate walking plenty of fluids and good nutrition. Prayer and inspiration a must
- Get up and move
- Just keep life as normal as possible..
- I would have taken more supplements prior to treatment.
- Move more
- Nutrition and sleep and rest.
- Sleep when tired and stay away from sugar
- Keep as active as you possibly can
- Take time to rest and give yourself a break
- Extra sleep
- I eat healthy and try to exercise every day it really helps me but sometimes is not easy for me to start, i have to encourage myself
- Do not PLAN on working! Take the time you need to just stay in bed & sleep.
- Rest as much as possible

- Rest as you need it and don't push yourself.
- Good diet and multivitamins
- 4 years now in treatment journey, I would probably have started asking for medication when started.
- Stay rested, hydrated and exercise kiwi
- Did research on that food to eat
- Exercise more and eat healthiest food
- Eat well & lots of water
- I worked while doing chemo. The fatigue happened more after it was over and a few years later I retired. I shared my journey with everyone and that helped a lot
- Follow treatment options with an open mind.
- Exercise & drink lots of water
- To eat fresh foods and no processed or junk foods
- Nutrition-exercise
- Don't know
- Start exercising asap to keep ahead of it.
- Eat healthy and sleep as you feel too.
- Be sure and rest. Exercise if you can force yourself to do so
- Stay busy
- Doctor can help to encourage the patient
- Tough to avoid, as it's often accompanied by other issues like bone pain (in my case)
- Moderate exercise, eat and sleep well
- I think fatigue is part of treatment. I rested a lot through chemo and didn't feel guilty about it.
- Get out the house get fresh air
- Get help from different doctors
- Exercise regularly, be hydrated stay in touch with alkaline water eating food when it necessary
- Get plenty of rest
- Find a way to stay motivated to walk daily.

Contact us

For additional information, please contact us at info@belong.life