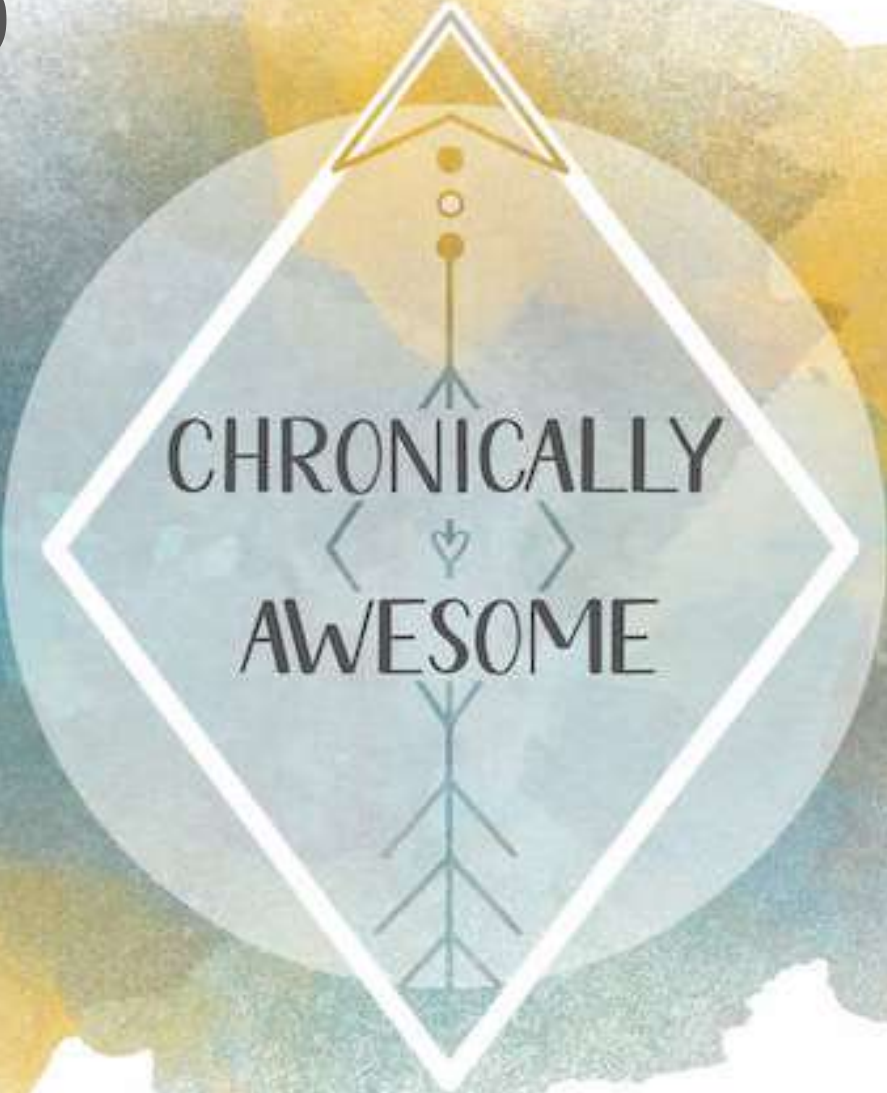


Market Research

Published March 2020

2019





About this research

This research was conducted by
Chronically Awesome

Registered charity no. 1188337

www.chronicallyawesome.org.uk

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basis

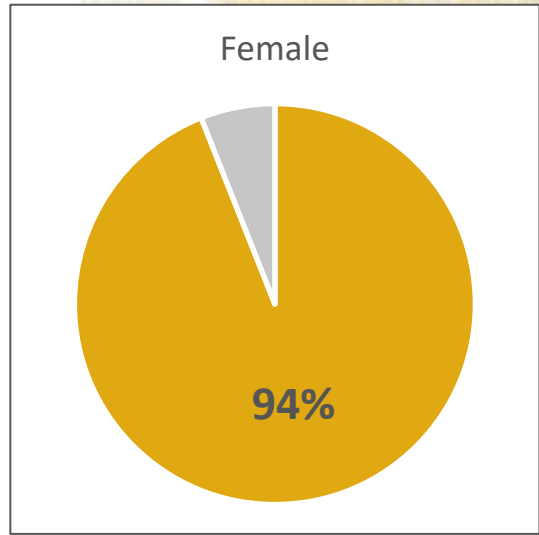
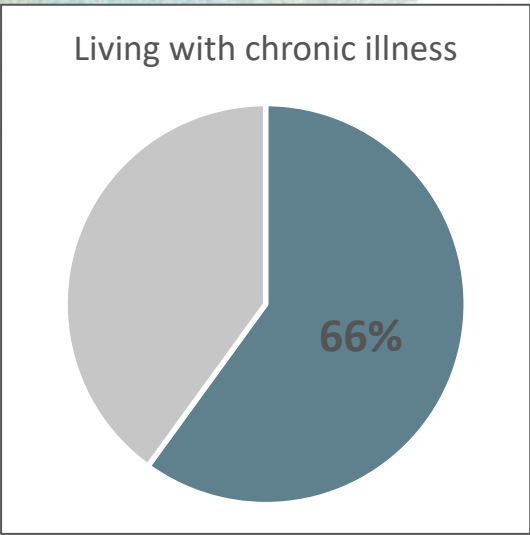


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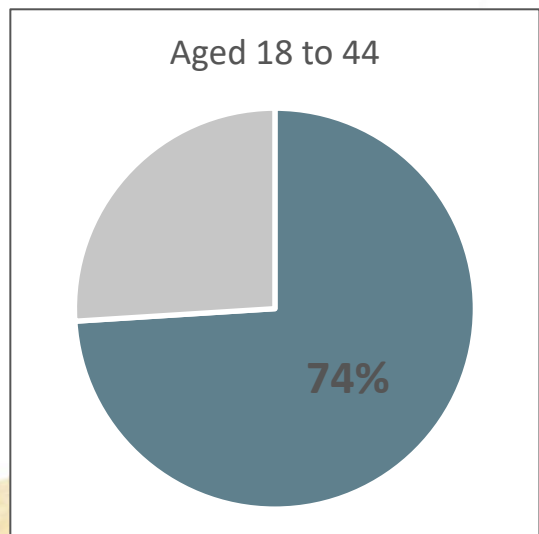
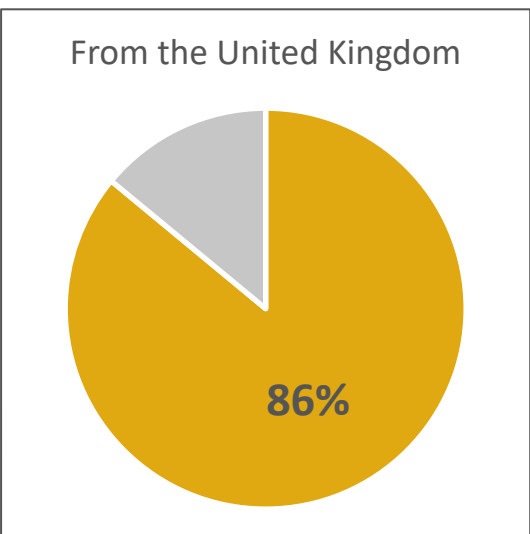
- **Executive summary**
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- **People living with chronic illness:** About their illnesses.
- **Friends and family:** About them and their loved ones living with chronic illness.
- **Colleagues:** About them and their colleagues living with chronic illness.
- **Professionals:** About them and the people living with chronic illness that they support.
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- **Food and nutrition:** Needs of sufferers and current practices.
- **Mental and emotional health and relationships:** Needs of sufferers and current practices.
- **Navigating work:** Needs of sufferers and current practices.



Executive Summary



685 respondents





People said...

I just want to say I think this & what your doin is absolutely incredible. Thank you

“Just completed it, very insightful questions”

I think the voice you are trying to raise for people is fantastic!

I think you got it down to a tee

“... you guys seem to really care I cant wait to see new ideas they will really help.”



Your symptoms and what you find helps ease them

- More than two thirds of us suffer with fatigue (83%) and depression and/or anxiety (75%)
- 62% of us suffer with joint pain, and 57% of us suffer with muscle pain and/or generalized pain
- More than half of us experience dizziness or light headedness (53%), stiffness (53%, migraines and/or headaches (53%), reduced mobility (52%) and loss of strength (52%)
- More than a third of us experience bloating (44%), constipation (42%), diarrhea (41%), nausea and/or vomiting (40%), weight gain (36%), intolerances or allergies (35%) and abnormal heart rate (35%)
- More than half of us say that the following help our symptoms: rest / sleep (87%), medication (80%), keeping stress levels low (75%), heat (e.g. heat packs) (62%), time with family and friends (52%)
- More than a third of us say that the following help our symptoms: diet (45%), mobility (38%), exercise (37%) and warm weather (36%)
- More than a quarter of us say that the following help our symptoms: counselling (29%) and physical therapy (26%)



How Illness Impacts Your Life

- Almost two thirds of us feel discriminated against because of their illness sometimes, often, or all the time
- More than half of us struggle to complete every-day tasks such as washing and cooking often or all the time
- 58% of us depend on others for care, help, financial support etc. often or all the time
- 55% of us feel financial insecure often or all the time
- 84% of us take medication often or all the time
- More than half of us take medication with negative side effects often or all the time
- 43% of us have to spend a lot of time and energy managing their illness (e.g. going to appointments and having tests) often or all the time



How family and friends support us, and would like to be supported themselves

- 87% of our family and friends support us emotionally
- Half of our family and friends said they help us with chores outside of the house (e.g. food shopping)
- More than two thirds of family and friends help with food preparation and/or home organisation (e.g. house keeping, laundry etc.)
- Almost a third of family and friends go to appointments with us, and/or assist with healthcare (e.g. overseeing or administering medication etc.)



Exercise, movement and chronic illness

- 83% of us struggle to maintain a healthy level of movement and exercise
- Only 8% of us manage to maintain a healthy level of movement and exercise
- More than 60% of us said our main aims of exercising were to be healthier, to get fitter, to get stronger, to feel better about our bodies and/or to lose weight
- Of the two third of us who were told to get fitter, stronger or more active, more than half were given no instructions or guidance
- The classes / activities most recommended by healthcare professionals are swimming (49%), yoga (38%), walking (37%) and Pilates (32%)
- Only 30% of those who did the activities recommended by their healthcare professional said they helped
- Only 5% of the people who were told to get fitter, stronger or more active were able to do this quite or very successfully. 51% weren't very successful or at all.
- We lack energy (65%), motivation (36%) and/or confidence (26%). We can't afford it (37%). We can't get to classes or the gym (23%). We don't know how (20%). There aren't classes that can be adapted to our needs / limitations (15%) and/or we can't find the right classes (13%). There aren't personal trainers who can adapt training for my needs/limitations (14%).



Chronic illness, food and nutrition

- Almost 70% of us struggle to maintain a healthy body weight
- 60% of us struggle to maintain a health diet
- Almost 60% of us say we have a negative relationship with food
- More than half of us say that what we can eat and drink is restricted, and 46% of us skip meals because of our symptom(s) or illness(es)
- Our biggest barrier to eating better is cost
- Almost half of us struggle to know what to prioritise in our diet. 45% of us lack confidence in ensuring we meet our dietary requirements
- 45% of us say that our ability to prepare a meal is a challenge when trying to eat better
- The biggest priorities when searching for recipes online are how quick and easy it will be to prepare, time to prepare, whether the recipe is appropriate for my dietary requirements

Chronic illness and mental health

- 39% of us have been misdiagnosed as having depression and/or anxiety
- 86% of us feel like we will never amount to anything or achieve anything
- 43% of us have not sought help for mental, emotional, and/or psychological difficulties for fear of having physical symptoms wrongly labelled as psychological
- 95% of us feel lonely and/or isolated
- 41% of us have experienced post traumatic stress disorder (PTSD) as a result of our illness and/or treatment
- 39% of us have been misdiagnosed as having depression and/or anxiety
- 86% of us feel like we will never amount to anything or achieve anything
- 43% of us have not sought help for mental, emotional, and/or psychological difficulties for fear of having physical symptoms wrongly labelled as psychological
- 95% of us feel lonely and/or isolated
- 41% of us have experienced post traumatic stress disorder (PTSD) as a result of our illness and/or treatment



How well supported do you feel in education, training & employment

- Three quarters of us said we lack support to get back into employer
- Half of us said we lack support to staying in employment
- 45% of us said we lack support to keep up at work
- Half of us don't feel supported in managing our finances
- Two thirds of us don't feel supported to get back into education or training
- 46% of us don't feel supported to stay in education or training
- Almost half of us don't feel supported to keep up in our education or training



How chronic illness affects us at work

- Almost 80% of us say that chronic illness affects us in our work
- 36% of us said that we have had to give up work entirely because of our illness(es)
- 47% of us said that we cannot take on as many hours at work as we'd like
- More than a third of us haven't been able to pursue the job or career we trained for or wanted because of our illness(es)
- 29% of us said that our illness(es) have disadvantaged us at work. 47% of other people said that they thought our illness(es) have disadvantage us at work
- Almost a third of our friends and colleagues etc. think that we feel discriminated against because of our illness(es) in the area of work
- 27% of us said that we struggle to get back into work because of our health. 42% of other people thought that we struggle to get back into work because of our health
- 21% of us said that we struggle to hold down a job because of our health. 37% of other people thought that we struggle to hold down a job because of our health

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Methodology



Methodology

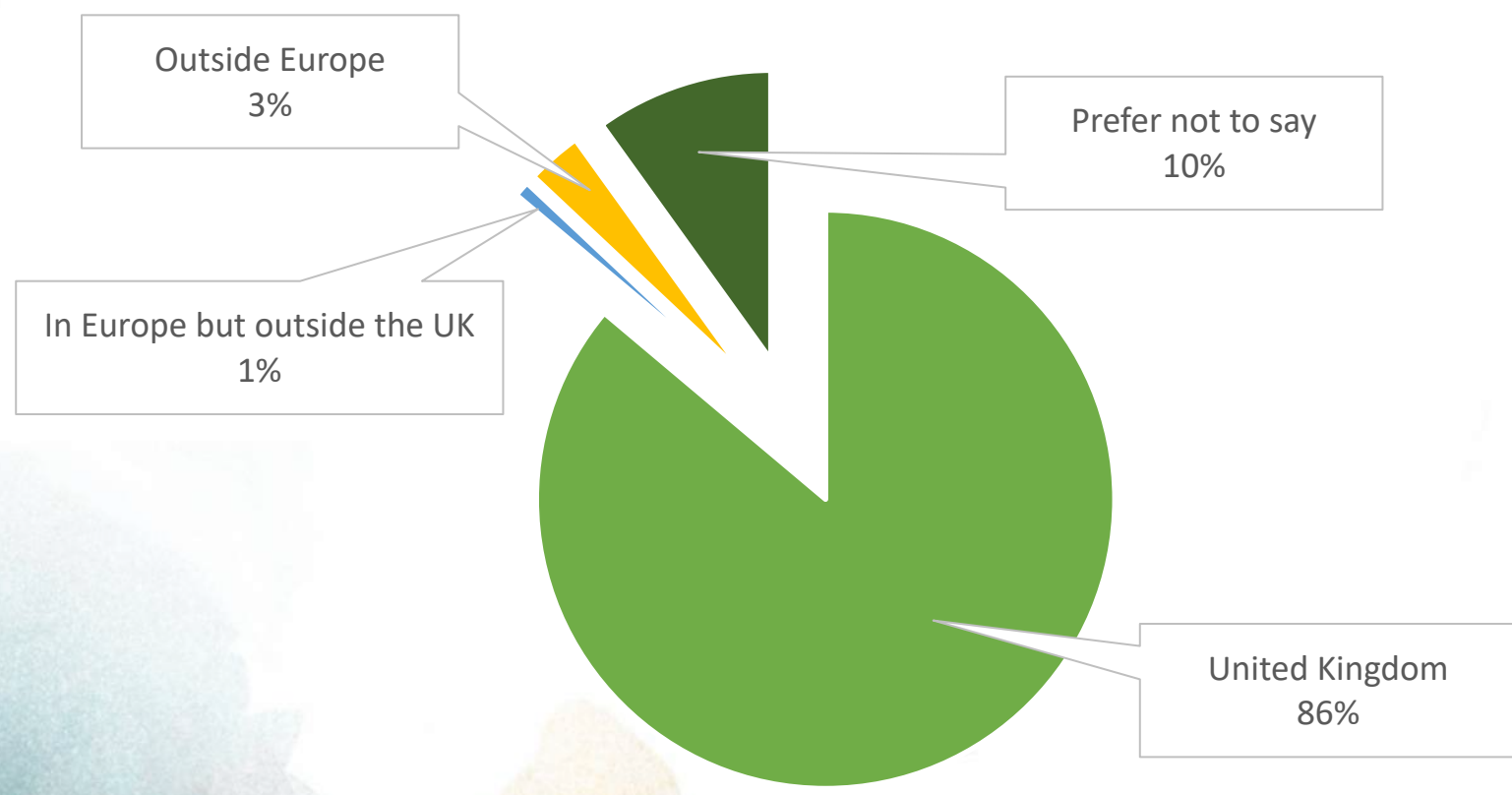
- Online survey using [SurveyMonkey](#)
- Designed, delivered and analysed in-house
- Advertised on social media (Facebook and Instagram)
- 113 questions
- 685 responses in total, 38% completion rate and an typical time spent 14 minutes
- Respondents segmented:
 - People living with chronic illness
 - Friends and family of people living with chronic illness
 - Colleagues of people living with chronic illness
 - Professionals who serve people living with chronic illness
- One lucky respondent received a Care Package of goodies worth £180
- Output material is published on a creative commons attribution, non-commercial, share-a-like (CC BY-NC_SA) basis



Demographics of respondents

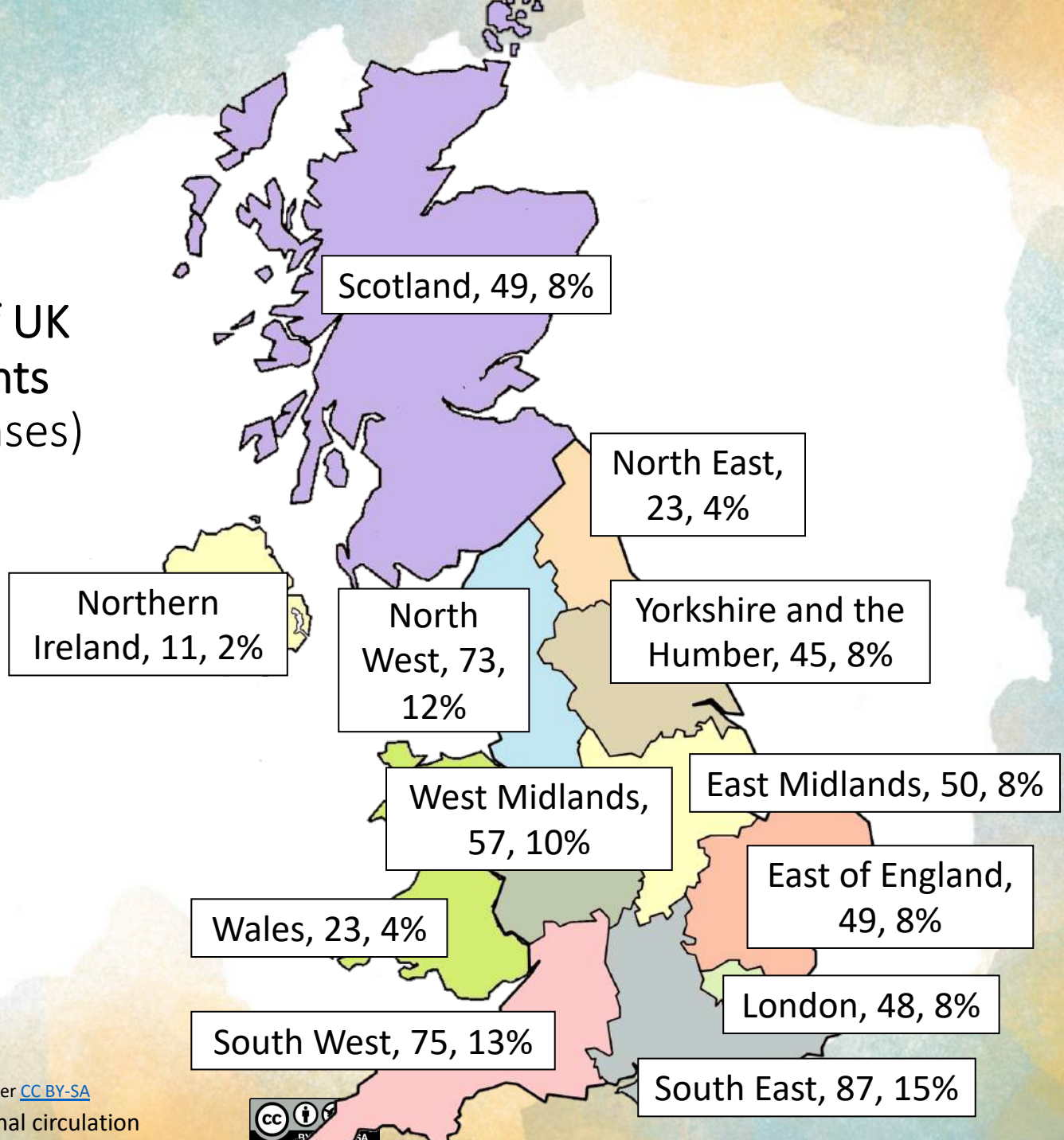


Location of respondents (685 responses)





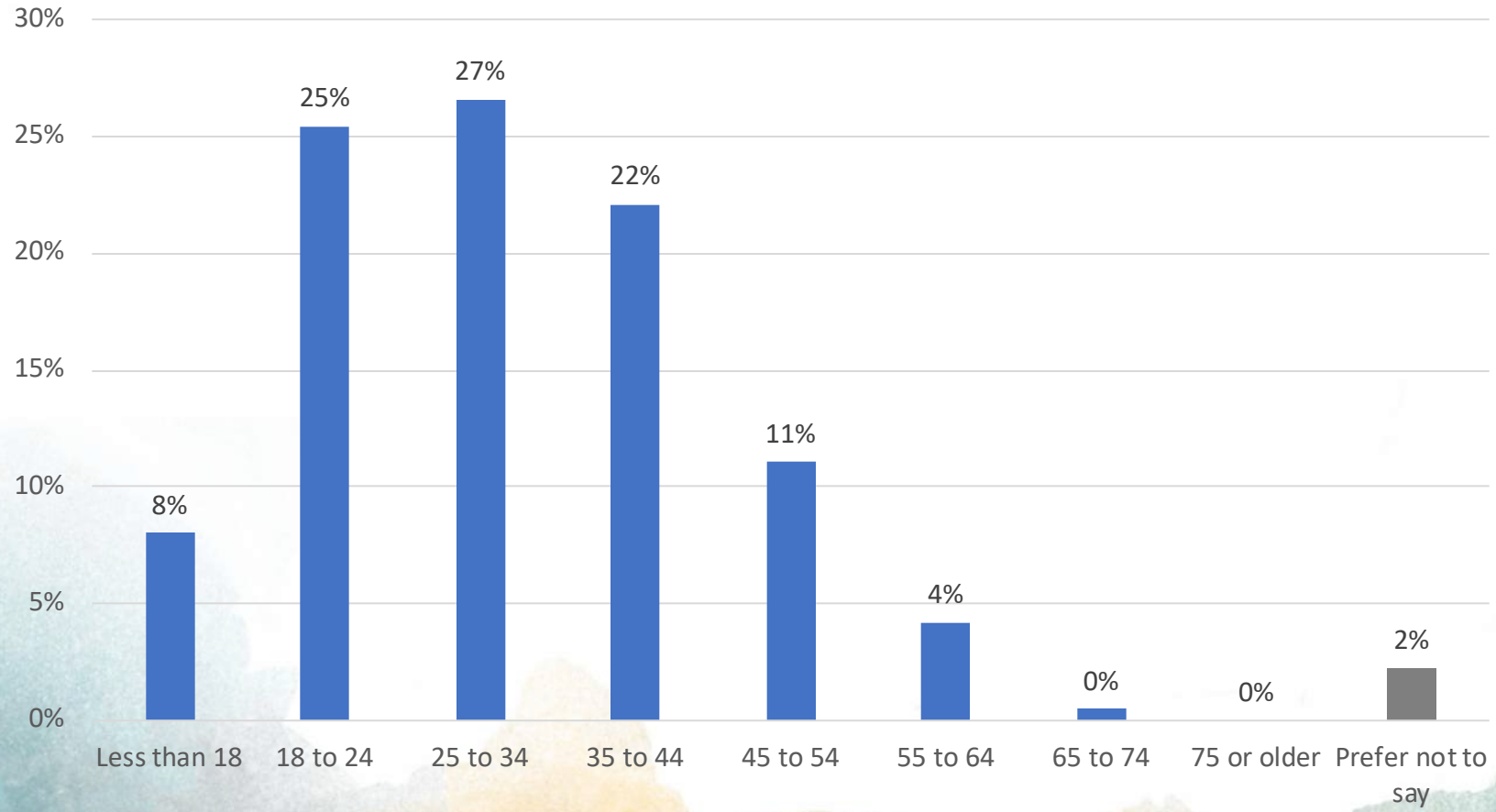
Location of UK respondents (590 responses)





Age of respondents

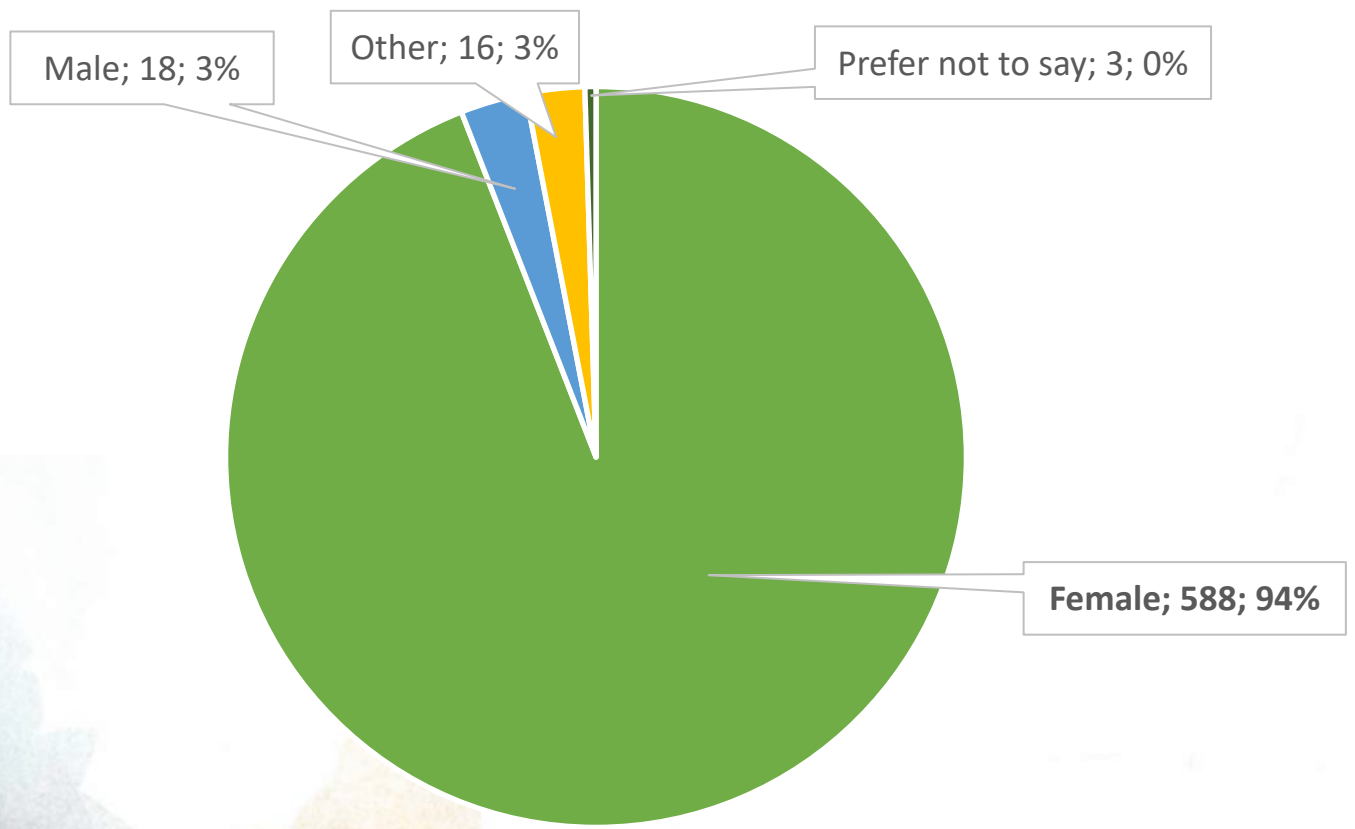
What is your age? (625 responses)





Gender of respondents

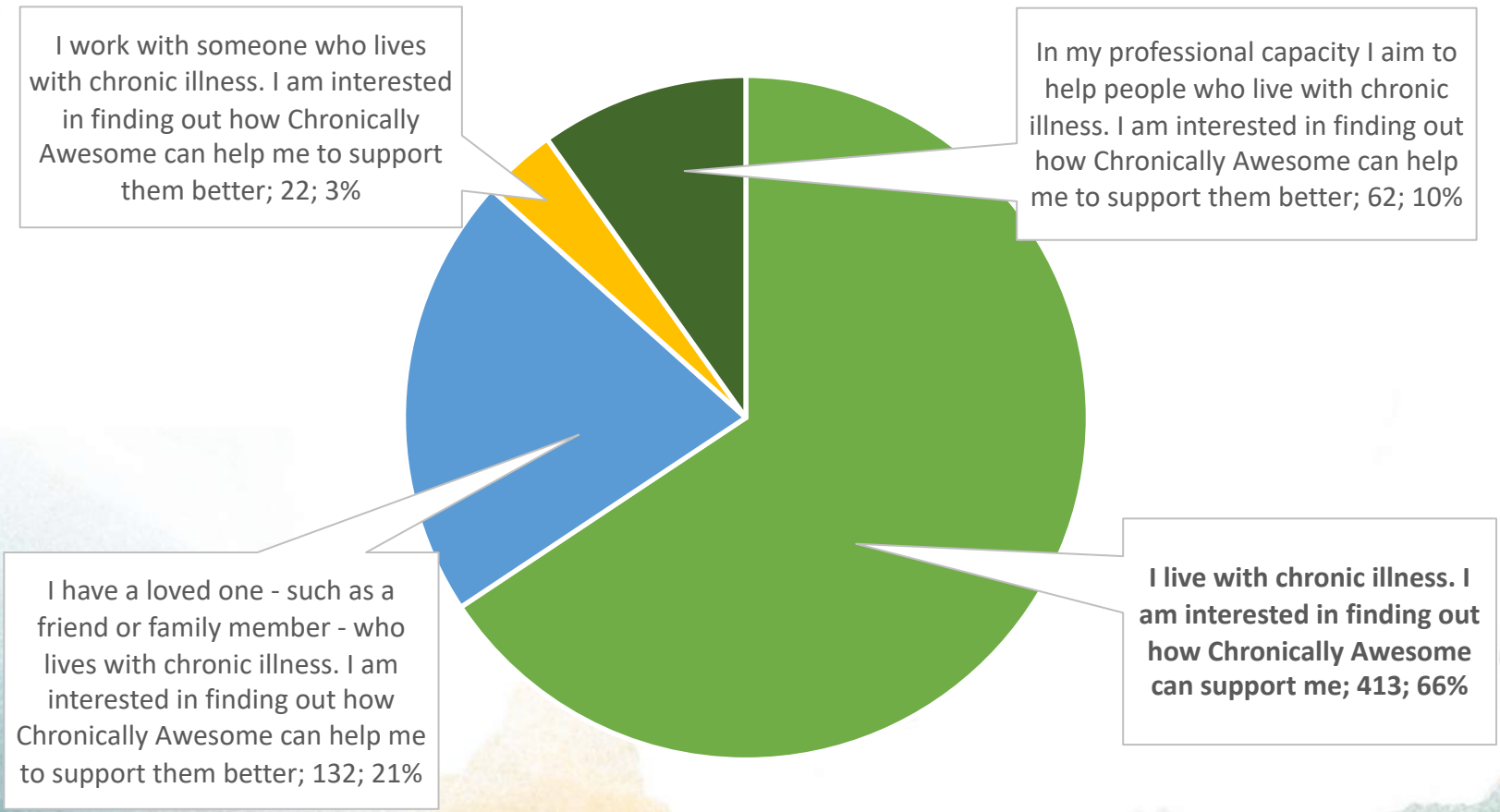
What is your gender? (625 responses)





Responder Segments

Which of the following best describes you?



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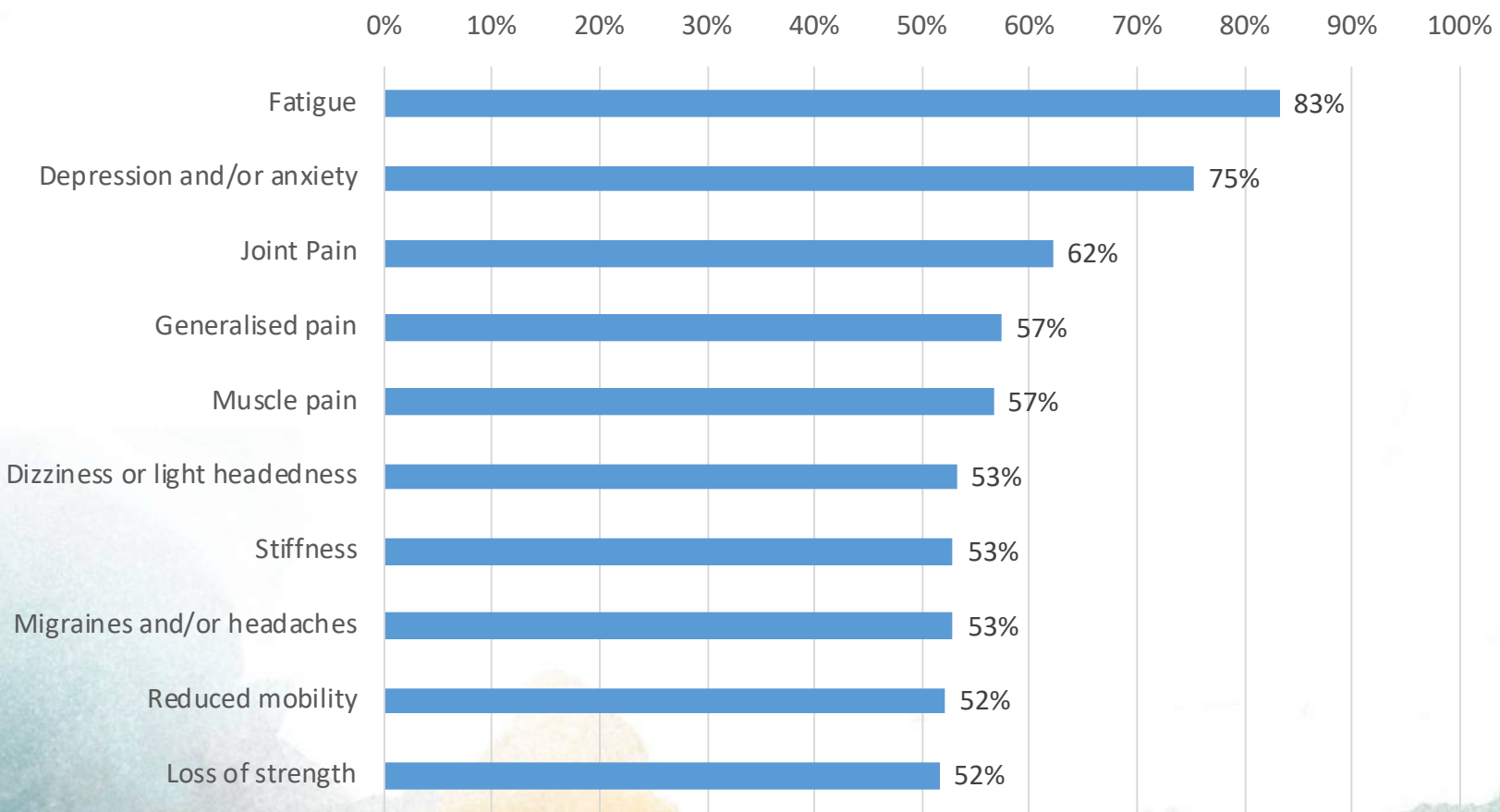
People living with chronic illness

About their illnesses



Symptoms

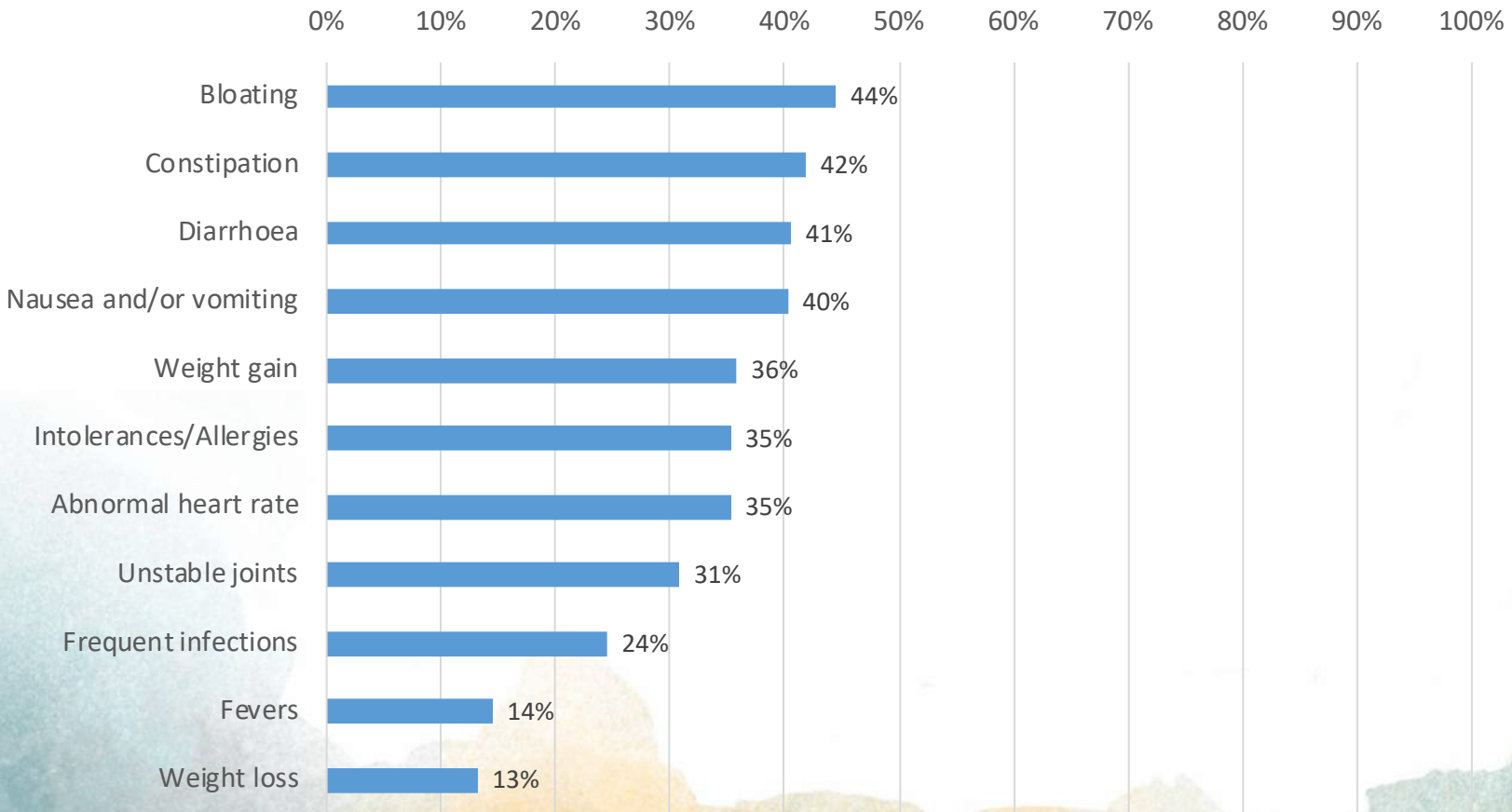
What symptoms does your illness (or illnesses) cause you? (380 responses) (Part 1: most common)





Symptoms

What symptoms does your illness (or illnesses) cause you? (380 responses) (Part 1: less common)

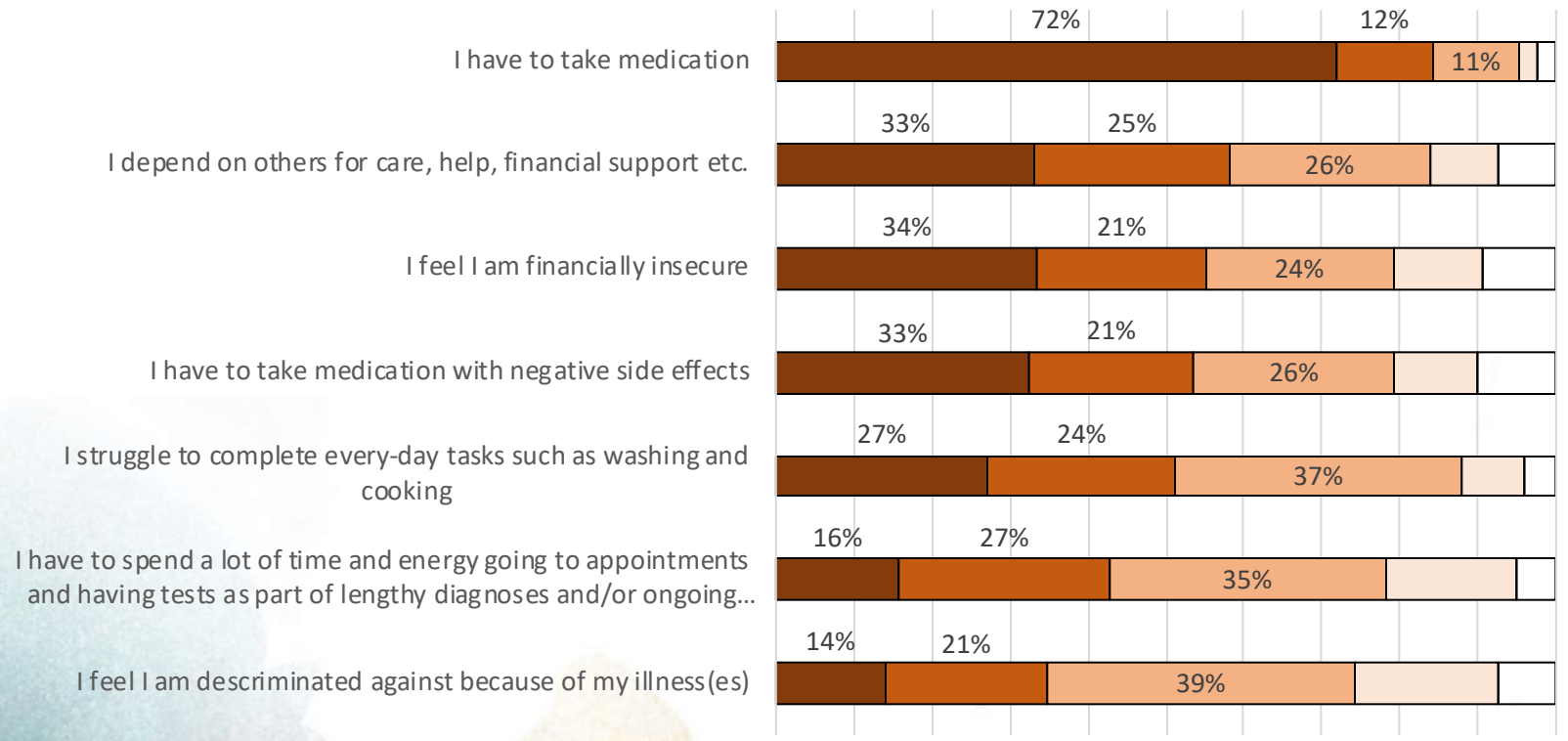




Impact of illness

How does your illness (or illnesses) and symptoms impact on your life? (380 responses)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%



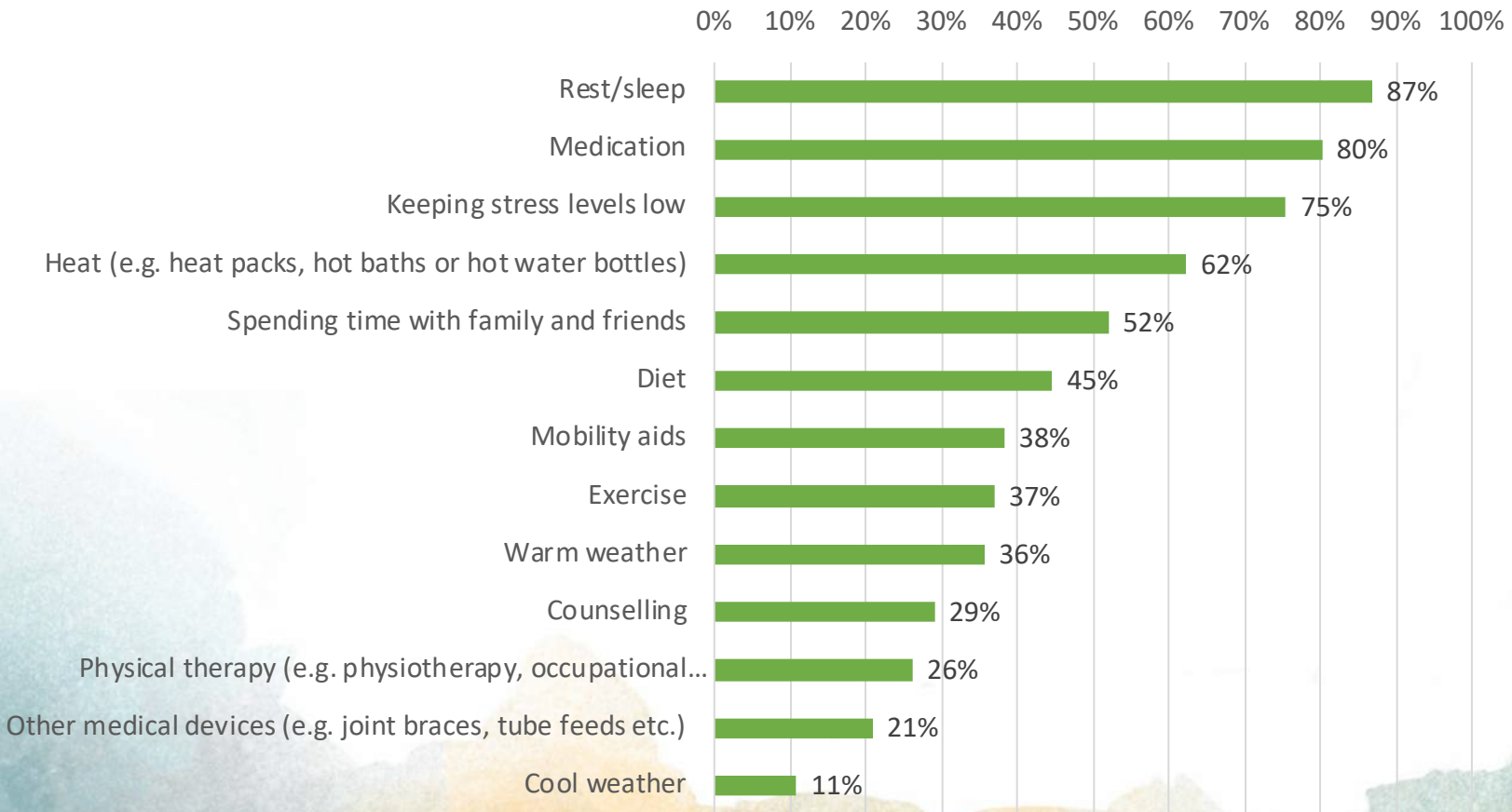
All the time
 Often
 Sometimes
 Not very often
 Not at all





What helps

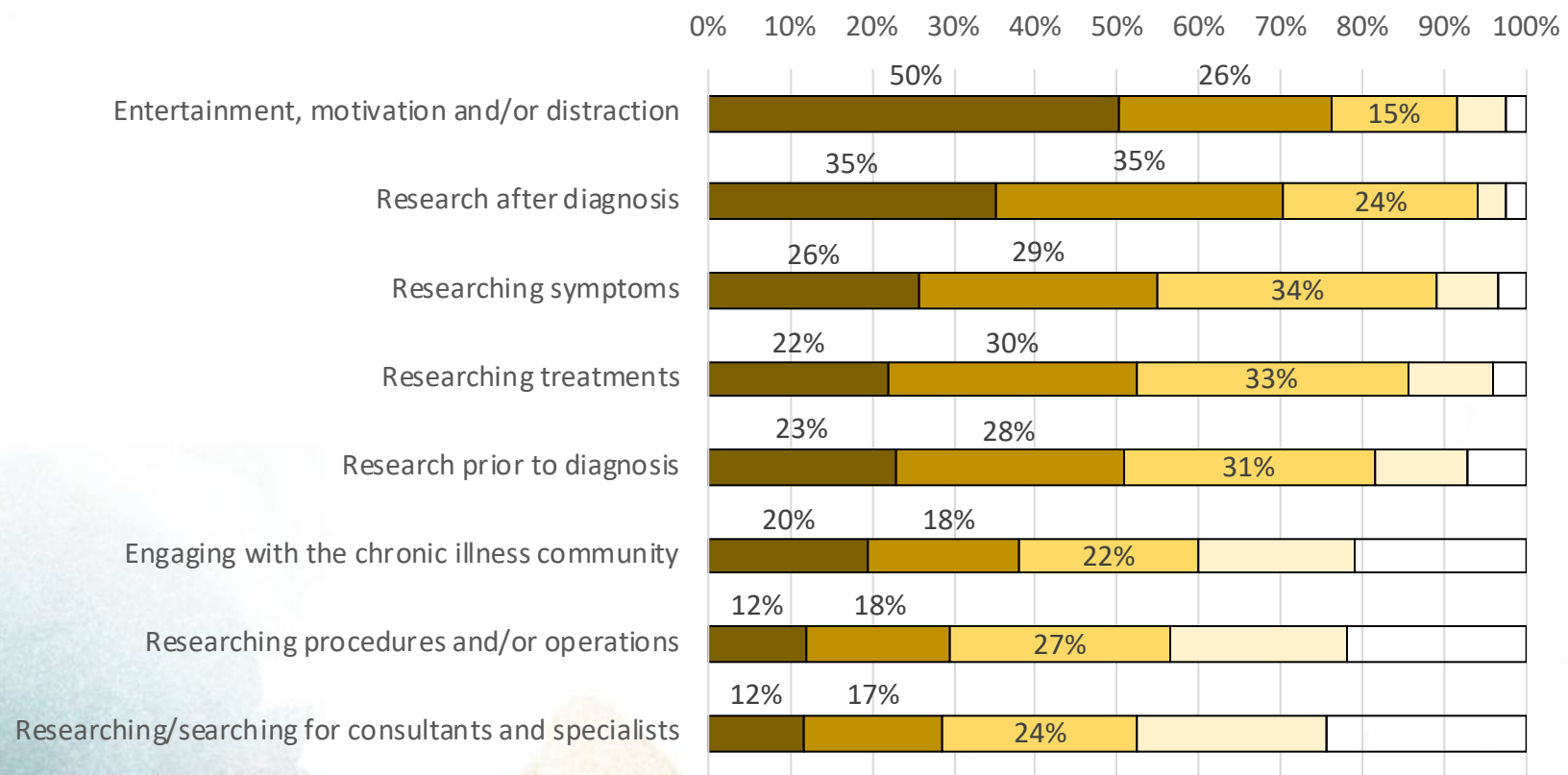
What helps your symptoms? (379 responses)





Sufferers' use of internet

How often do you use the internet for the following reasons? (377 responses)



Very often
 Often
 Sometimes
 Not very often
 Not at all

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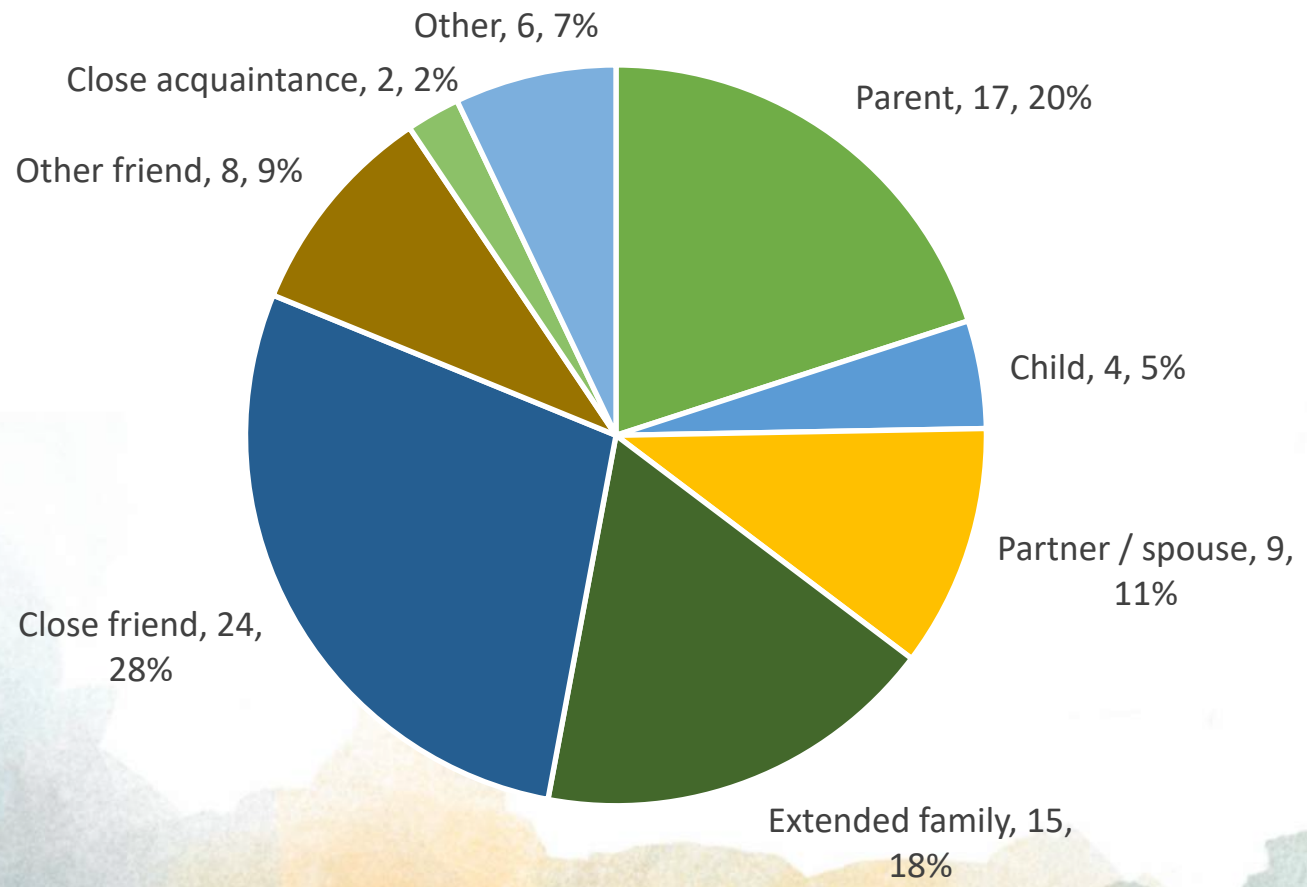
Friends and family

About them and their loved ones living with chronic illness



Friends and families' relationship with sufferer

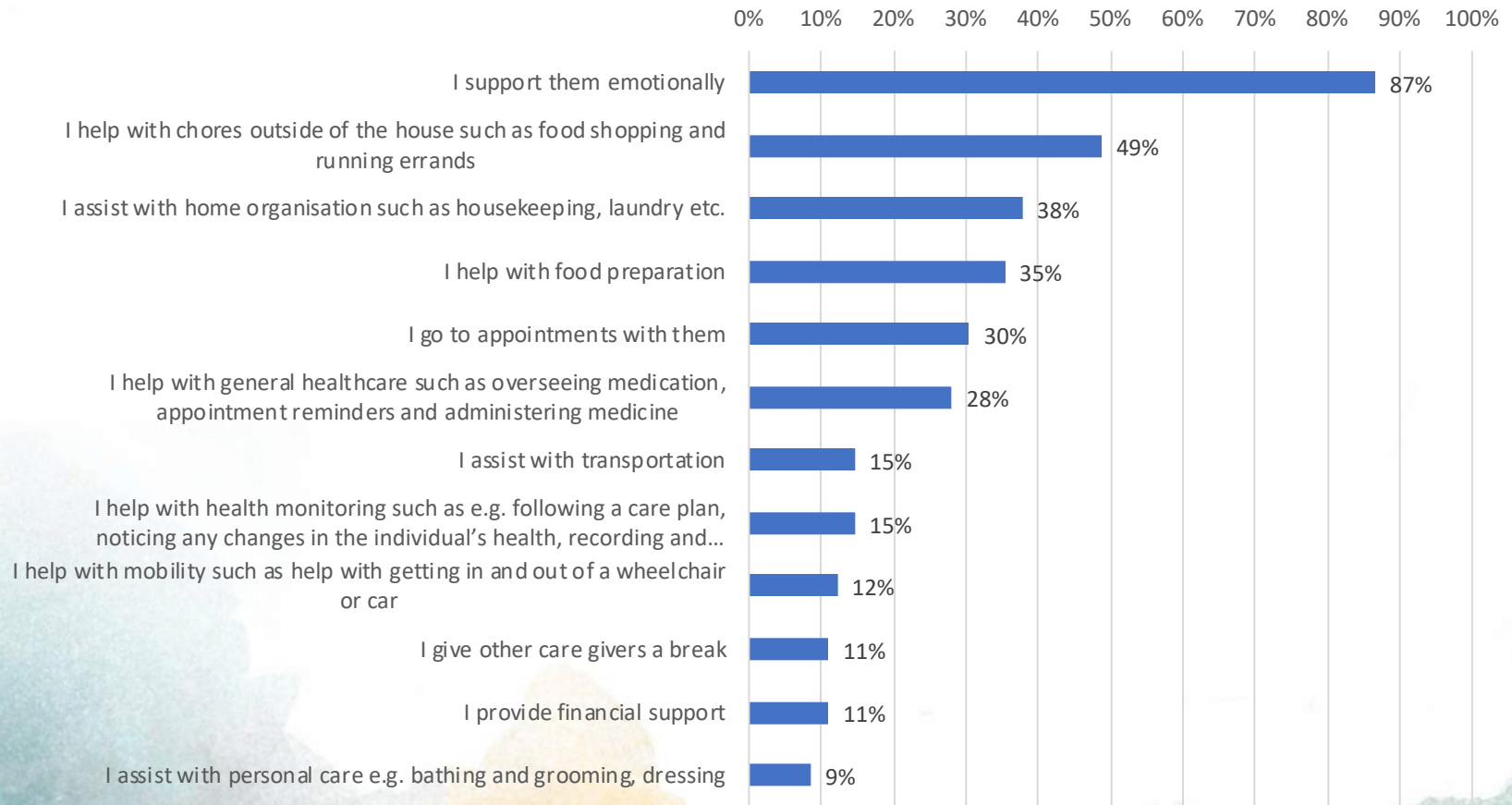
What is your relationship with the loved one (or loved ones) who live with chronic illness? (83 respondents)





Friends and families supporting sufferers

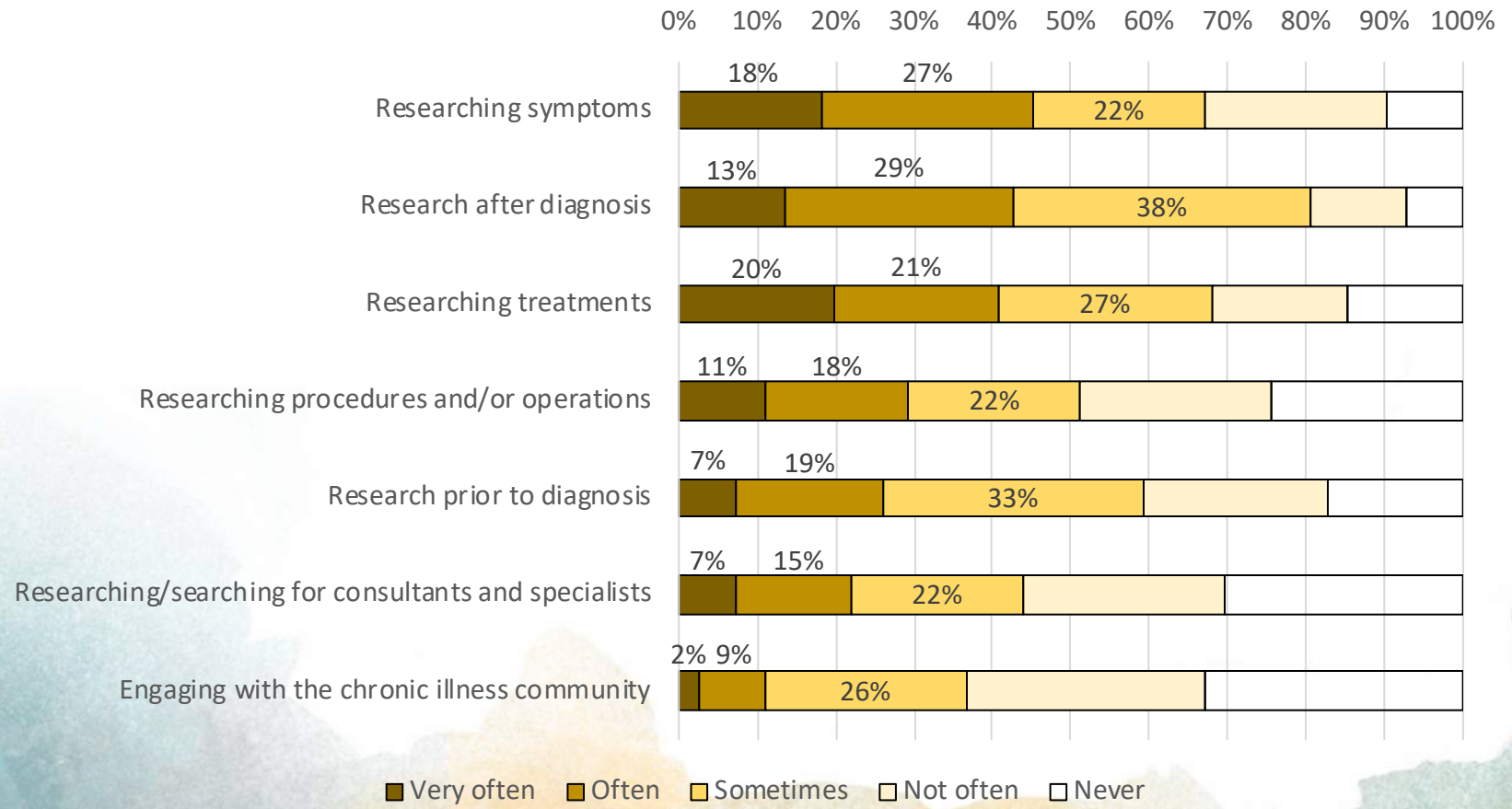
How do you support your friend/loved one? (82 responses)





Friends and families' use of internet

In relation to your friend or loved one's illness, how often do you use the internet for the following reasons? (82 responses)





How do you think the illness (or illnesses) of your loved one (or loved ones)?

The illness is invisible so they are often worried that others will see them as 'attention grabbing'

She doesn't get to live the life she wanted.

My friend is a really happy person but her relationship with her chronic illness can be described as grieving, and that breaks my heart to see.

It stops them doing the things they love

Demotivation,
withdrawal, guilt

Definitely has damaged
their confidence

They are currently unable to work or leave the house.
They are sad and frustrated about their illness

It shadows what they do and
the way they think.

It stops them
doing the things
they love

It's terrible and effects
them everyday

It sucks the life
out of my
husband

It has major impact when it comes to going out or do something away from home, especially at meal times when they'd like to treat themselves they have to think so logically and plan ahead for literally everything

Makes life unbearable at times
and makes every day a
struggle.

They are sometimes unable to do things that we would invite them to do due to their illness



How, if at all, does your loved one's chronic illness(es) and symptom(s) affect your life?

Feeling sorry, helpless

She gets mad a lot and takes it out on us because of the pain and we can go out that much because we don't have the money since she can't work that much or because she's in pain

It affects us all as a family, as we need to arrange everything around our child's needs

The worst thing was watching their health deteriorate as there was nothing I or anyone else could do about it; I found that really difficult to deal with.

(Trying not to have a gallows laugh) I'm her full time carer, her illness derailed her whole life making basic tasks like bathing impossible some days. She's my mum who raised me as a single parent, who has loved the bones of me my entire life....so I've derailed with her.

It can make me feel
very lonely

I feel powerless to make him better. I work full time and am his carer when I'm home.

I feel compelled to defend them and make them feel understood and less alone

I always worry about what could happen to him, whether he is in any pain. I dream about the days we went on long walks by the river in the winter when mum was at work. I will never see him walking again.

A lot of emotion a lot of tears and worry and anxiety

Knowing that hurts so much, he loved nature. He was always out hiking in Dartmoor



Are there any skills or mechanisms of support that you would like to be able to provide to your friend or loved one that you can't now?

I need help to stop asking if she's ok every time she winces or is in pain. I ask way too much. She will let us know if there's anything

Emotional support

I'd like to do a course in counselling

Access to a garden as I believe it's a big pick me up

I think I need emotional support myself

A course to know how to properly care for them without hurting them

I wish I could've been able to drive as it would have made things a lot easier for them both if I could've drove them places so they could travel without having to walk far.

I wish I could take her travelling.

Financial

Id like a lot more information and a lot more cans and cants so we know before we try something if it makes her more uncomfortable

I'd like more flexible working hours so I don't have leave him so often.



How can we support you to better support your friend or loved one?

Help her get better and live a normal painless life

Making me feel understood and like I'm not the only one and it's worth it

More information on being there for them and how I can do more for them

Normalizing my experience and her experience. There doesn't appear to be many people in my age group caring for not elderly parents.

Reduce the stigma

How to help her with dealing with pain. Or how to help her carers my friends, with emotional or physical support

I would like training

I'm not sure what help I need

I wish I could be provided with more information on how to best help them in difficult situations, when their state is low or they're having a break down.

Share information about mental illness. People we meet need to be more kind!!

Let them know the support that is out there

Best way to take some time for self care without feeling guilty

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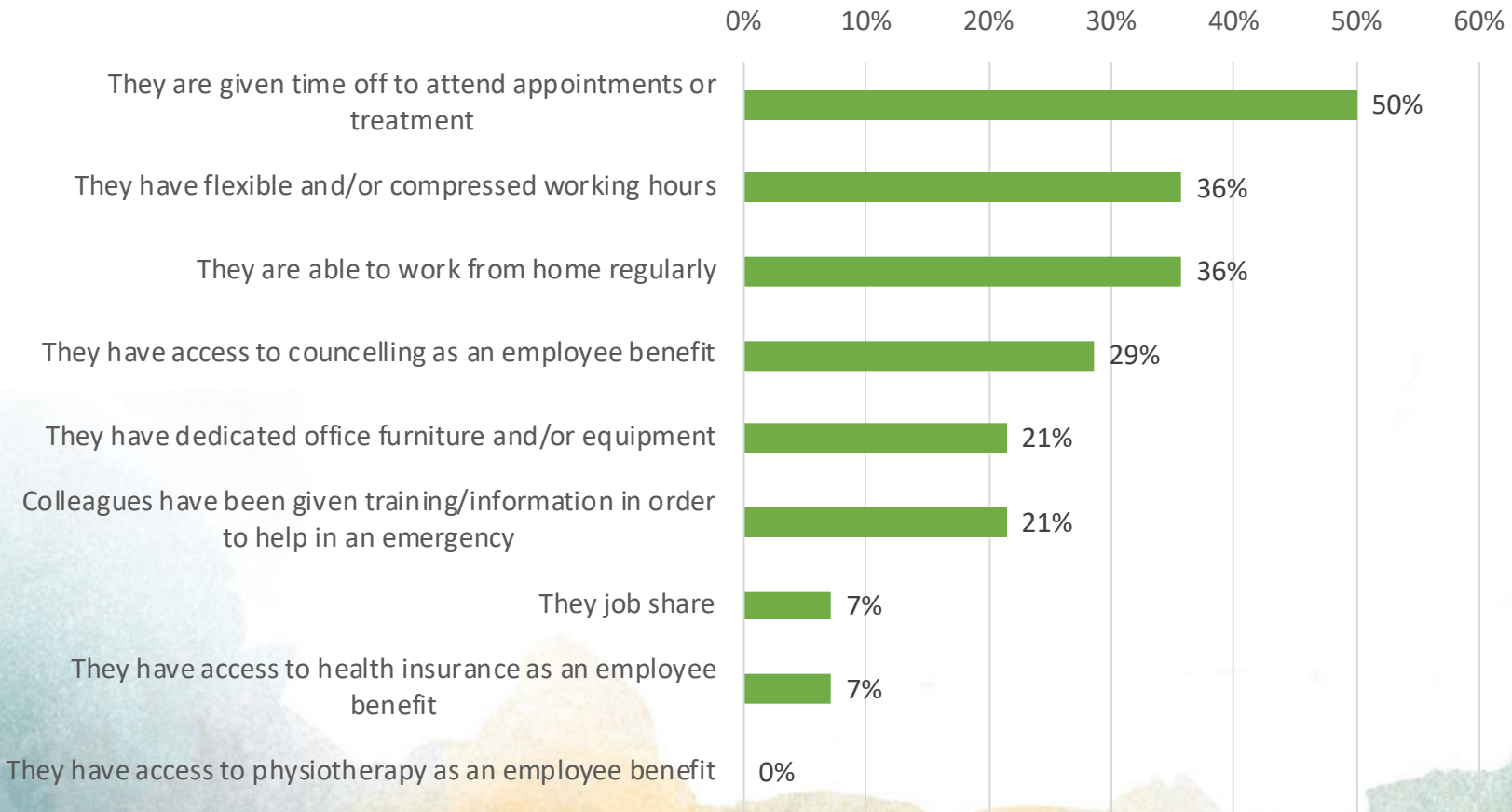
Colleagues

About them and their colleagues living with chronic illness



Colleagues supporting sufferers

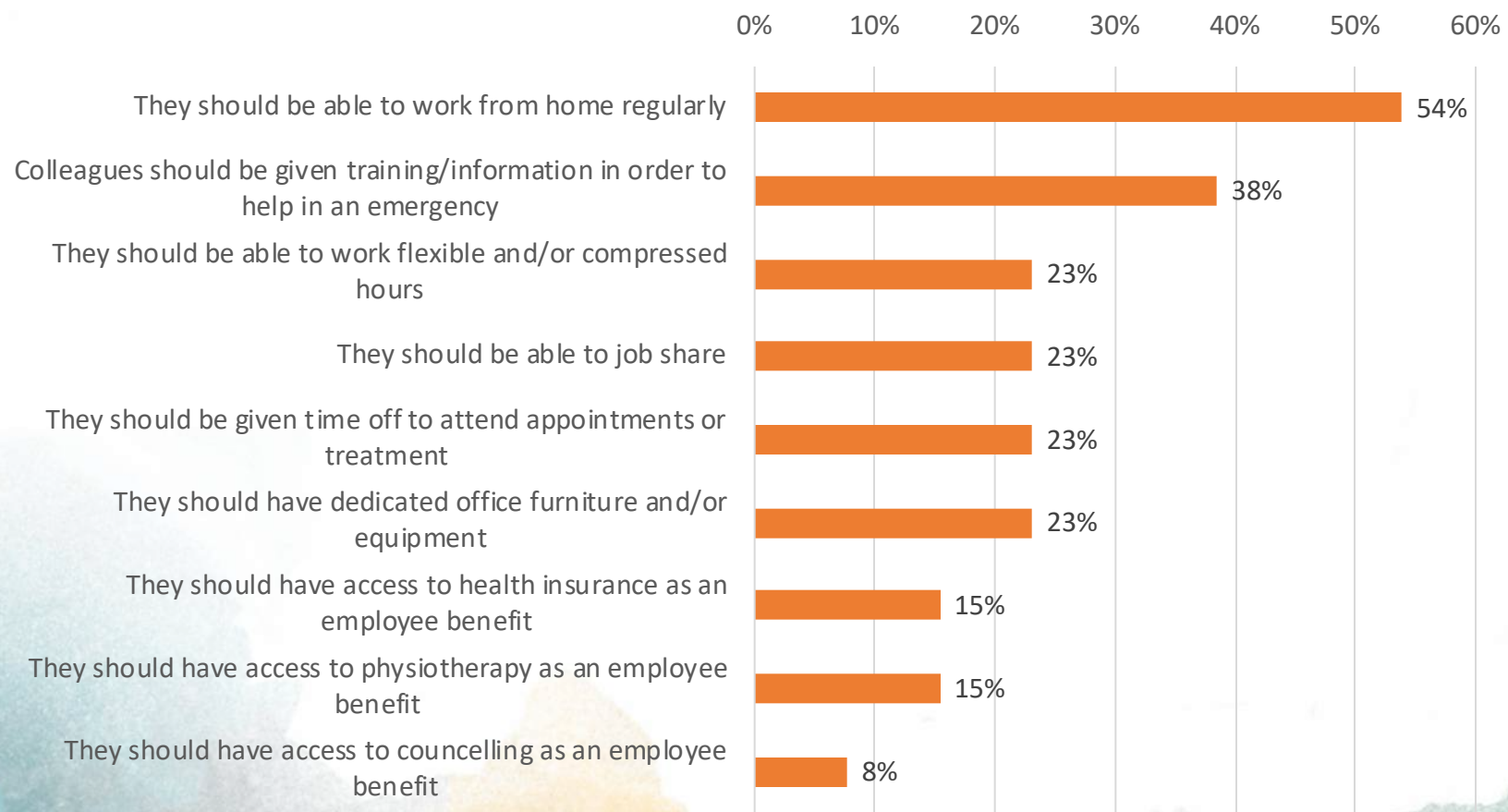
How do you and/or your employer support your colleague in their working life? (14 responses)





Improving support to colleagues

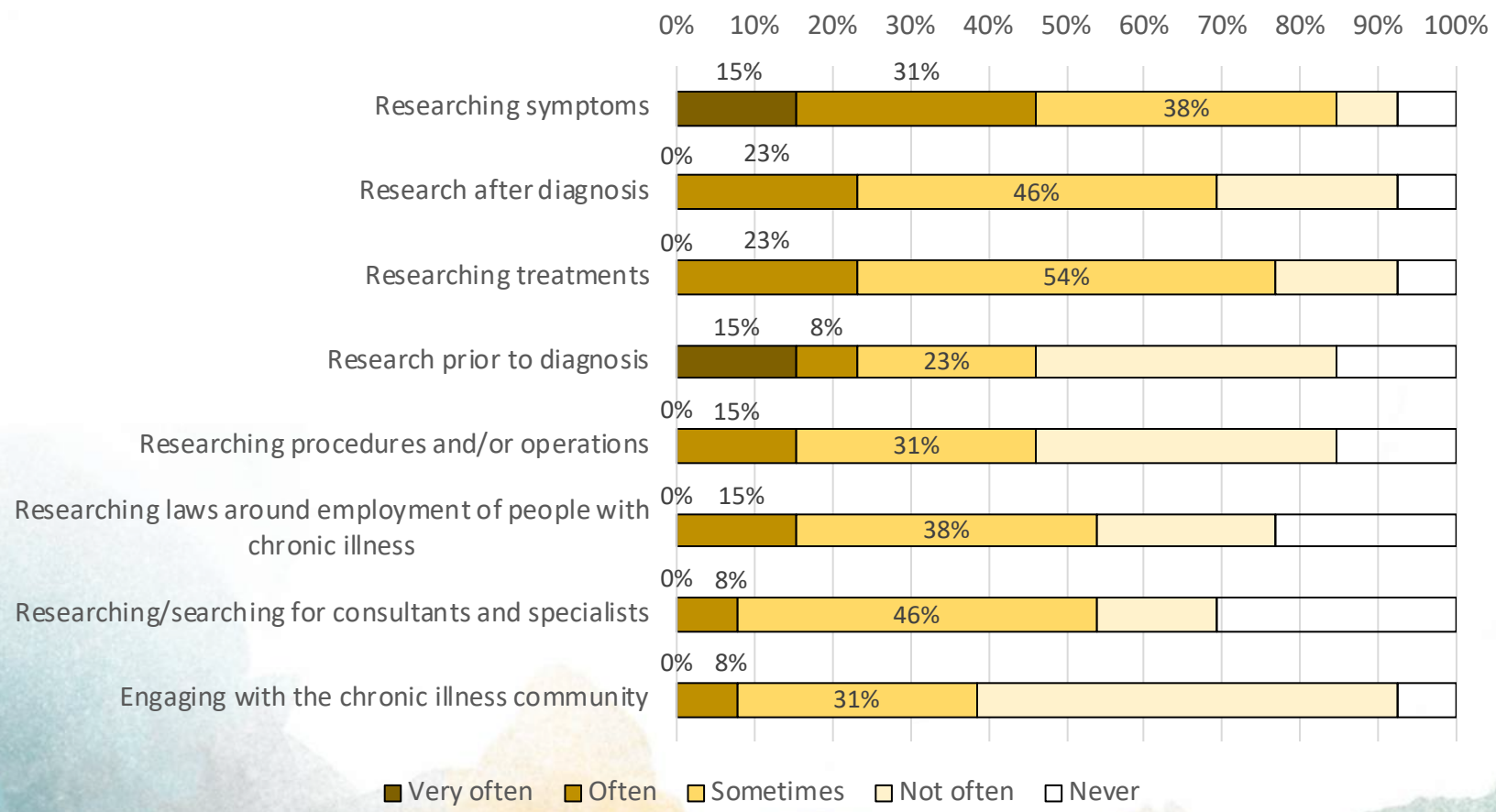
How do you think support could be improved for your colleague? (13 responses)





Colleagues' use of internet

In relation to supporting your colleague, how often do you use the internet for the following reasons? (13 responses)





How do you think your colleague's working life has been impacted by their illness(es)?

Inability to work full time or take on too much

They can't perform activities as quickly or efficiently

People assuming she cannot do certain things. She feels she cannot do certain things.

They don't perform as well in some areas and often find some tasks stressful.

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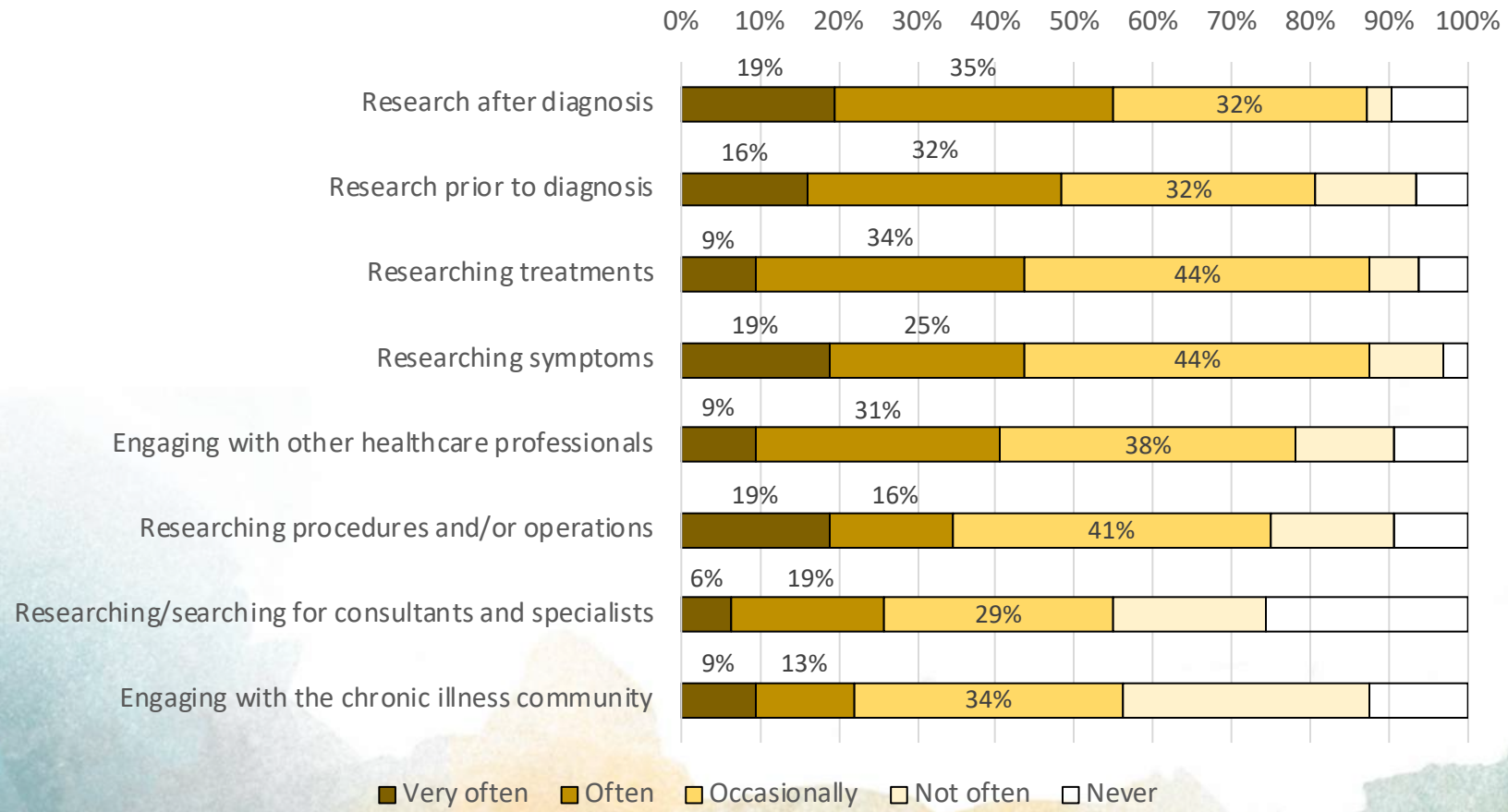
Professionals

About them and the people living with chronic illness
that they support



Professionals' use of internet

How often do you use the internet for the following reasons? (32 responses)





In what professional capacity do you aim to help people who live with chronic illness?

I am a midwife I frequently work with people who have chronic conditions both physically and mental health related

Physiotherapist

GP receptionist

I'm a dermatologist in training

Audiological scientist - mostly supporting patients in our balance clinic

GP

Nurse

I am a mental health nurse that work with children and adolescents. I am always trying to come up with creative ways to help my young people. I also suffer with chronic illness myself mentally and physically.
Anything I can do to help :-).



How many different people living with chronic illness do you estimate that you aimed to help in your professional capacity in the last 12 months?

- 2000
- 60
- 50
- 20
- 20
- 10
- 10
- 10
- 4
- 2



Stigma.

In your professional capacity, what gaps have you identified in the support available to people living with chronic illness to help them manage their illnesses and thrive?

Self care information

There are very limited resources for pregnant women to access resources for chronic illness

I've found there aren't many support groups and if there are they don't appear to be easily accessible

Little emotional support until it's too late

Counselling and empathy

Support groups

What social groups are available. What online resources or support

Multidisciplinary working so patients seeing multiple professionals individually to support the different aspects of their illness

I have actually found a complete lack of money to support those with chronic illness or disability in education. Our disabled toilet (complete with hospital bed) that is used for learners with diabetes so they can inject, as well as for disabled learners, didn't have a lightbulb for over a month. There was no mirror low enough for disabled learners to see themselves, & their main access point from the bottom half of our college was blocked with a metal podium in the floor. Money, emotional support from trained professionals, & understanding is lacking in education from management tiers. Lecturers & tutors are left to help as much as they can.

Education

Poor pain management and lack of use of alternative therapies



What gaps have you identified in the support available for your profession to effectively support people living with chronic illness?

Time to educate

Limited resources

It is very limited and only really mental health is being address at the moment all be it poorly

Home remedies

There absolutely is none. Our college does claim to focus largely on wellbeing & training in wellbeing, but in reality, we're not getting this because there's no money to properly train people in my profession. Further education is skint.

Time of appointments Lack of knowledge outside the practice

Education

Lack of support once you turn eighteen

No staff support- it hurts to see people in pain

Availability and funding.

Lack of easy access to professionals who know different conditions for expert advice



Movement and exercise

Needs of sufferers, current practices and demand for
Chronically Awesome support



Key findings

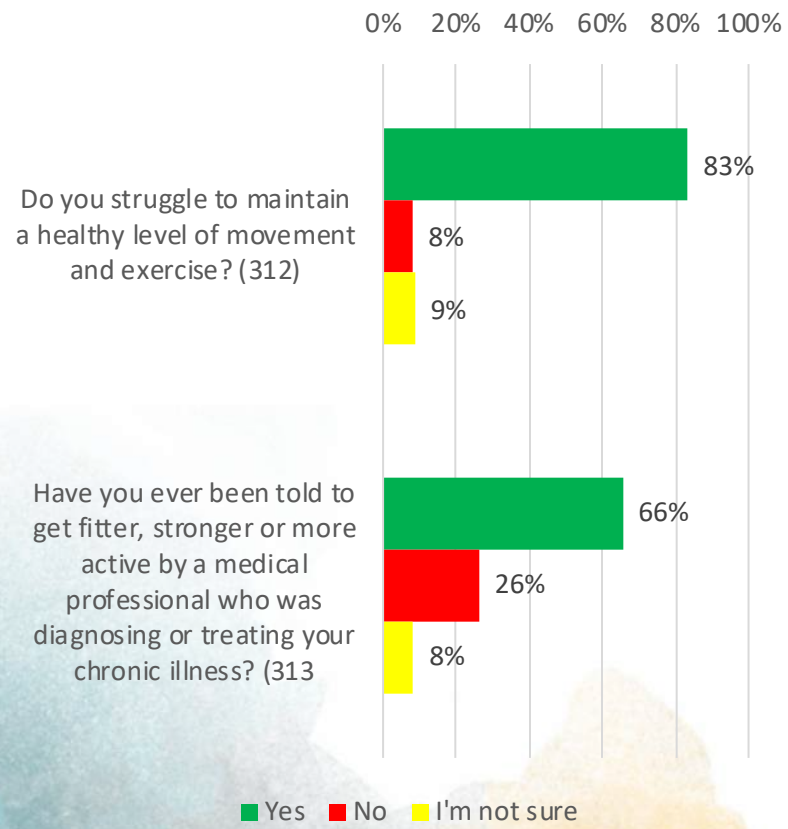
The need for support for movement and exercise

- More than three quarters of sufferers asked report struggling to maintain a healthy level of movement and exercise, and a two third report being told to get fitter, stronger, or more active by a medical professional.
- However, only 5% report being able to do so quite or very successfully compared to more than half reporting that they had not been successful.
- The biggest challenges sufferers report facing are a lack of energy, affordability, motivation. Three out of the top four reported challenges to getting fitter, stronger or more active are internal (energy, motivation and confidence).
- The three challenges reported least often are about not being able to find appropriate classes and personal trainers. They are perhaps not reported frequently because they are secondary to the internal challenges of energy, motivation, and confidence, rather than not being important.

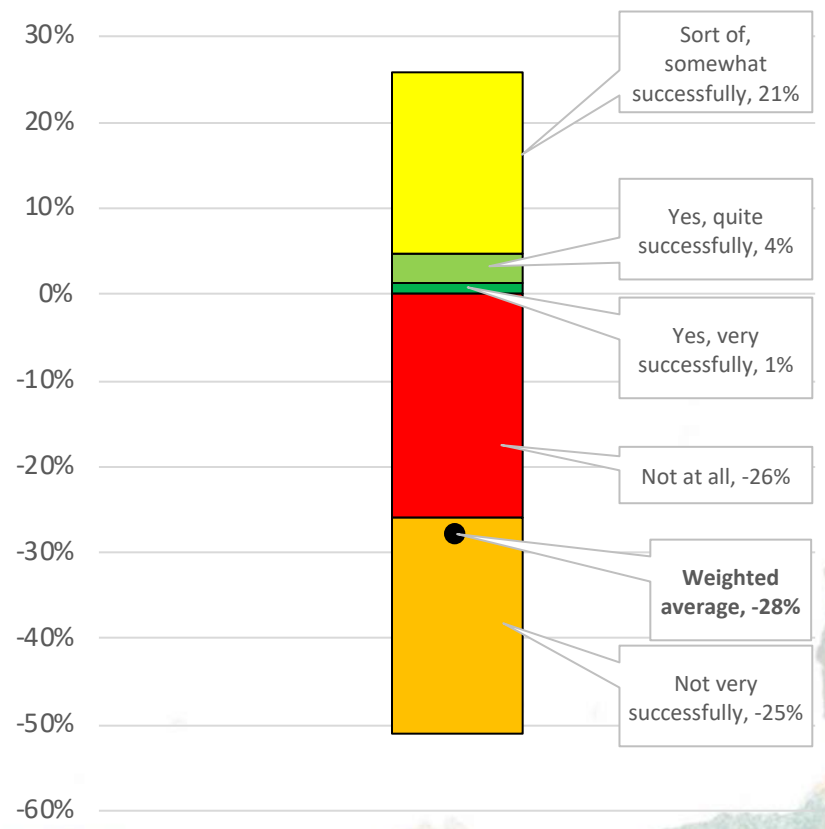


Movement and exercise prescriptions

Relevance of movement and exercise



Were you able to get fitter, stronger or more active as instructed by the medical professional? (313 responses)

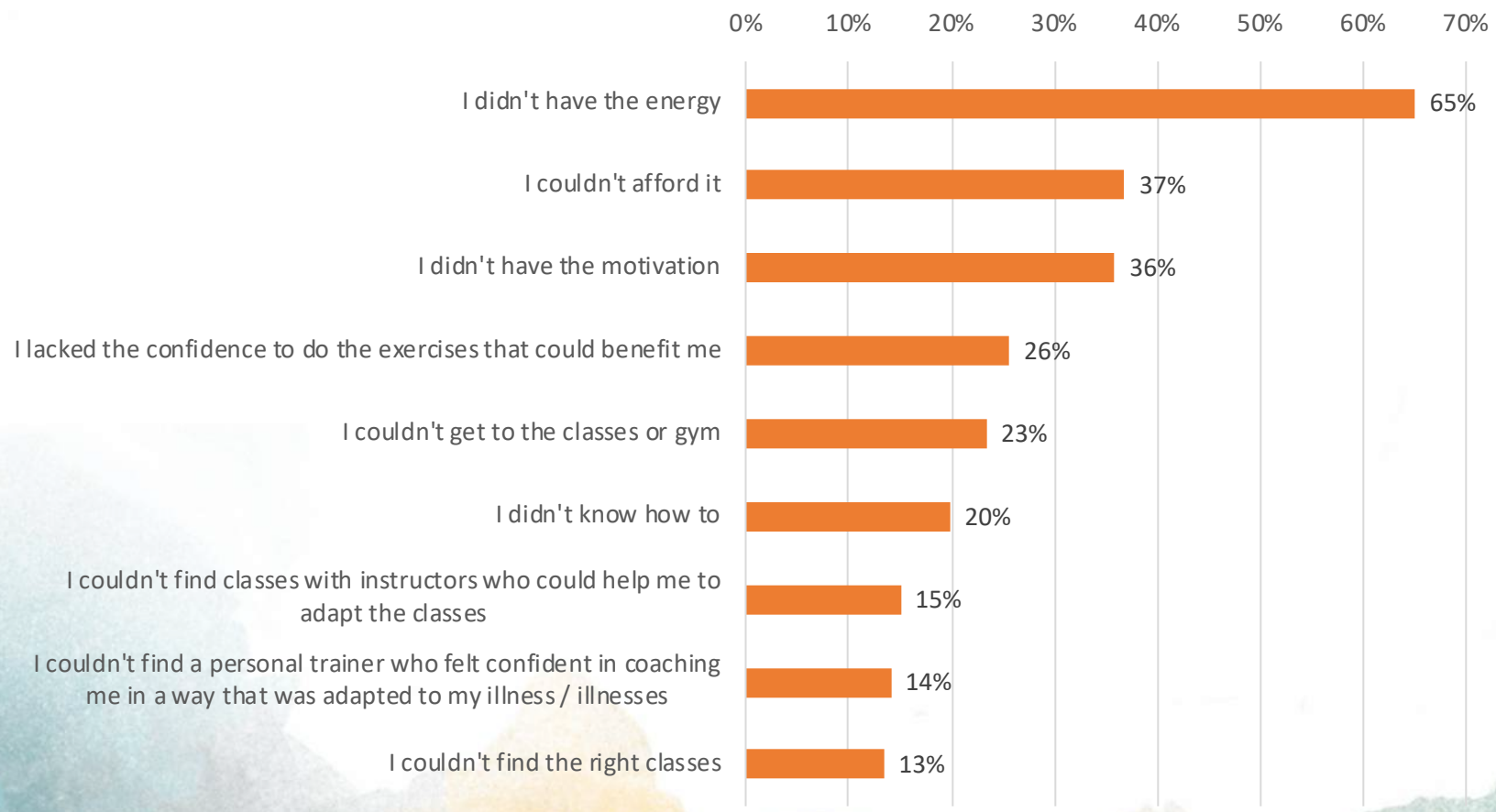


Question asked only of those who said an offering on movement and exercise would be very, quite or somewhat useful



Challenges getting more active

Why were you not or only somewhat successfully able to get fitter, stronger or more active as instructed by the medical professional? (264 responses)



Question asked only of those who said an offering on movement and exercise would be very, quite or somewhat useful

What organisations, services, websites, social media accounts and other resources do you already find useful in supporting movement and exercise in people living with chronic illness?

Instagram

My local library does tai chi / chair exercise class. It's gentle so I don't injure myself

Thistle Foundation

Hadn't actually thought to look for this until doing this questionnaire!

Youtube

FIIT App

Sadly not many. I'm having to pay an extensive amount to train to teach and including ones focused on chronic illnesses it's only in the teaching courses that I've found answers here in the UK and I've seen a lot of physios, pts, ect.

I haven't come across anything that supports people with chronic illness.

NHS

Fibromyalgia yoga class local to me

The Mighty

None

Blogilates

Facebook

Manchester Metropolitan university

Wii Fit

WhatsApp group from my inpatient stay



Key findings

A lack of specific guidance or instruction

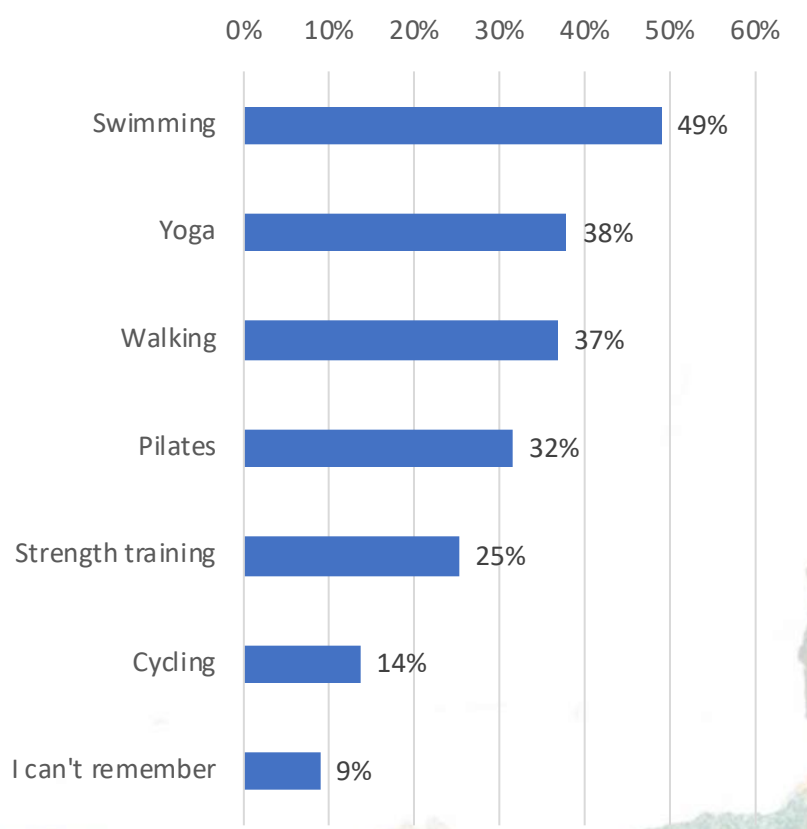
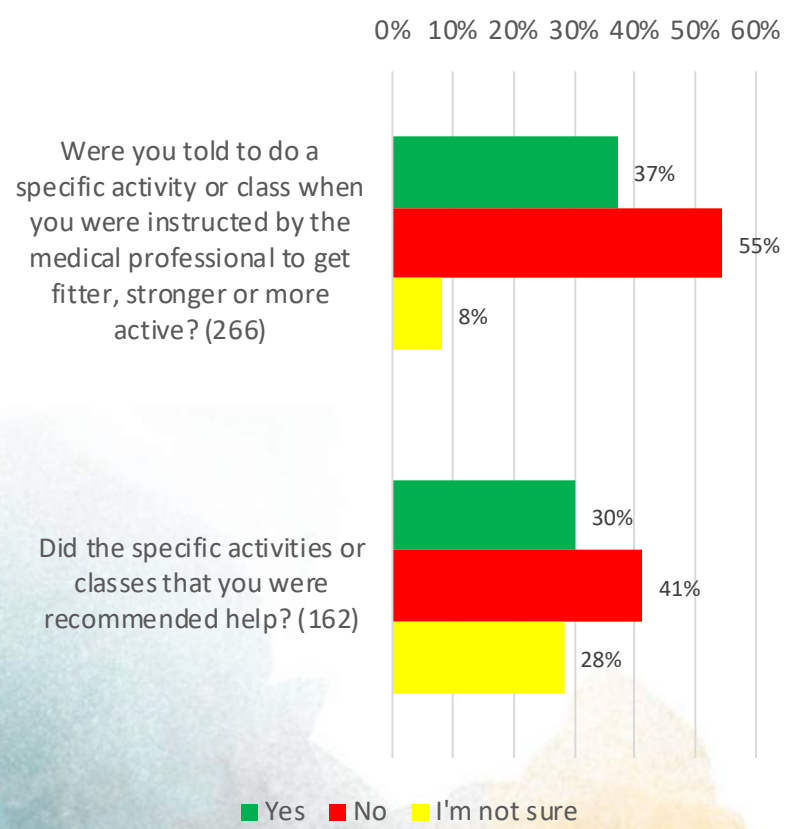
- Of the two thirds of sufferers told to get fitter, stronger or more active, more than half were not given specific instructions or guidance.
- More than a third of sufferers were told to do a specific activity or class, but less than a third of those report that this specific activity or class had helped.
- The top four activities or classes that were recommended were swimming, yoga, walking and Pilates.



Specific activities and classes

Specific activities or classes

Which of the following specific activities or classes were you told to do?
(190 responses)



*'Not applicable' responses excluded from analysis and count of responses
Question asked only of those who said an offering on movement and exercise would be very, quite or somewhat useful*





Why did the specific activities or classes that you were recommended not help?

I am scared to go to the gym and be judged. I am scared to go out alone for a walk so I avoid doing it.

I couldn't participate in them

I also have agoraphobia, and there are no classes available in my very limited safety zone

I was never assessed for correct muscle activation. I basically was bending into positions more rather than building and using supportive muscles. This isn't the fault of the exercises but the fitness instructors and physios I saw did not check I was doing it correctly.

I wasn't provided with specific activities to do - just told to exercise.

no classes for disabled people

Yoga and no chronic illness training equals bad yoga

Can't find classes suitable for me

Couldn't afford gym and too cold outside to walk

I have Asperger's so find it impossible to go swimming, plus financial strain - swimming pools aren't free!

i didn't participate as i don't have the confidence to go out.



Why did the specific activities or classes that you were recommended not help?

No guidance was given on what to do or how to achieve such a broad issue as 'lose weight'. It was very much left to me to figure out my boundaries and limitations, and what might be achievable from any help I could afford to source (gym membership & PT sessions).

Can't afford it

Not the type of exercise i needed to work on. Nothing was taken into consideration and tailored

Not tailored to my needs for my chronic illnesses

They mostly helped but it is hard to afford to swim twice a week when you are not earning.

Because I could not go regularly due to the pain and the cost

I'm hypermobile almost everywhere except hips and yoga really made this uncomfortable, plus the teachers didn't have any experience of EDS, Pots, hypermobility or how thyroid disorders affect your body and movement

Time, money, motivation, pain

i am exercise intolerant - no support in working with or through this

Haven't been able to access a Pilates class and don't have the money



Key findings

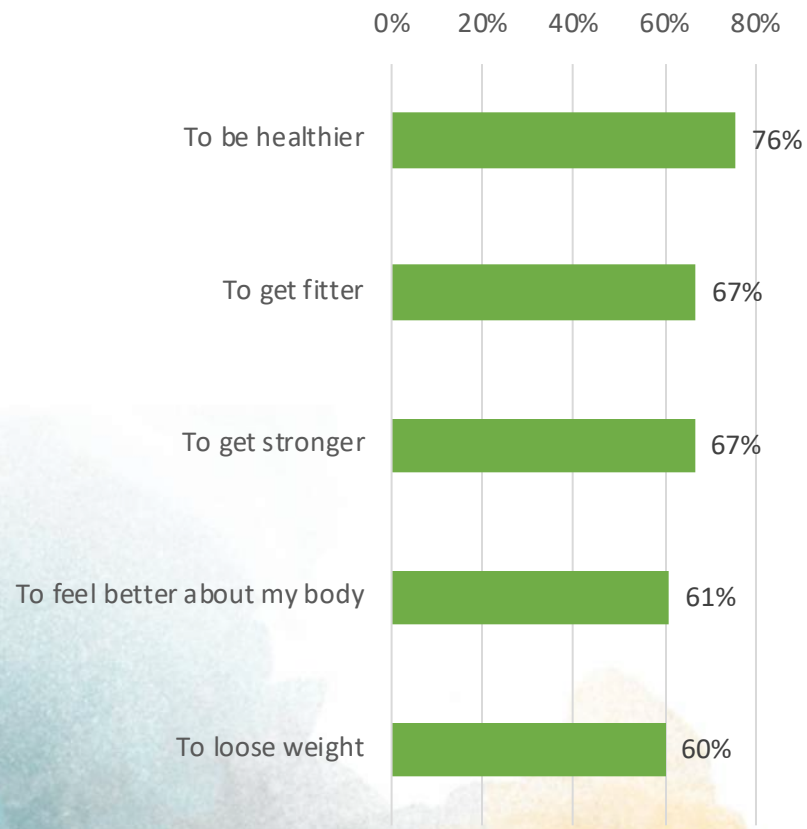
Where sufferers try to get fit

- By far the most common place and means of trying to get fitter, stronger or more active for sufferers is on their own, from where they live – three quarters of sufferers report this.
- 26% report attending group classes, 19% report working out at a gym on their own and 25% report working with a personal trainer.
- 31% of sufferers report trying to get fitter, strong or more active from their beds.

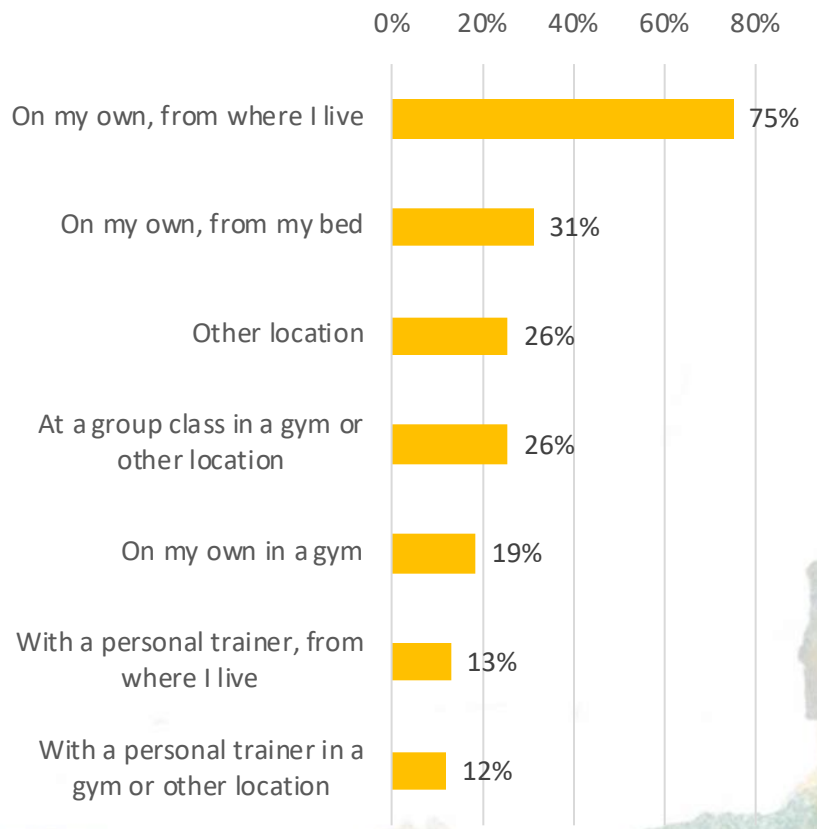


Movement and exercise: Where, how and why

What are / would be your main aim(s) of exercising? (tick all that apply) (308 responses)



Where and how are you likely to try to exercise to help you get fitter, stronger or more active? (308 responses)



Question asked only of those who said an offering on movement and exercise would be very, quite or somewhat useful

CHRONICALLY
AWESOME



Food and nutrition

Needs of sufferers, current practices and demand for
Chronically Awesome support



Key findings

The need for support on food and nutrition

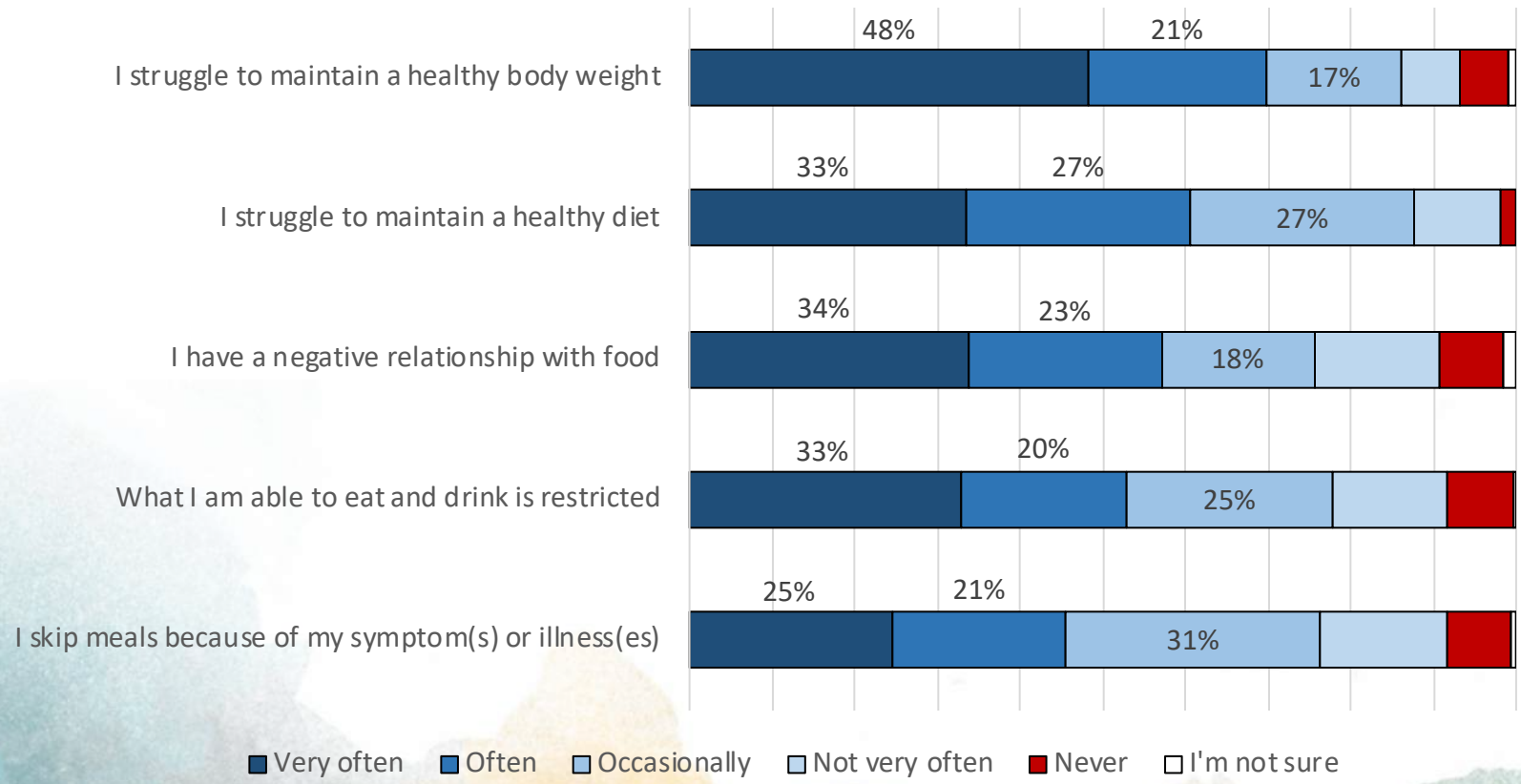
- More than half of sufferers asked report having a negative relationship with food and being restricted in what they are able to eat.
- More than two thirds struggle to maintain a health body weight and 60% struggle maintaining a healthy diet.
- Cost and ability to prepare a meal are common challenges that sufferers face in trying to eat better. More than half report cost being an issue.
- Almost half of sufferers report that it's a challenge knowing what to prioritise in their diet and having the confidence to ensure that they meet their dietary requirements.



Experiences of food and nutrition

How often do you experience the following? (284 responses)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

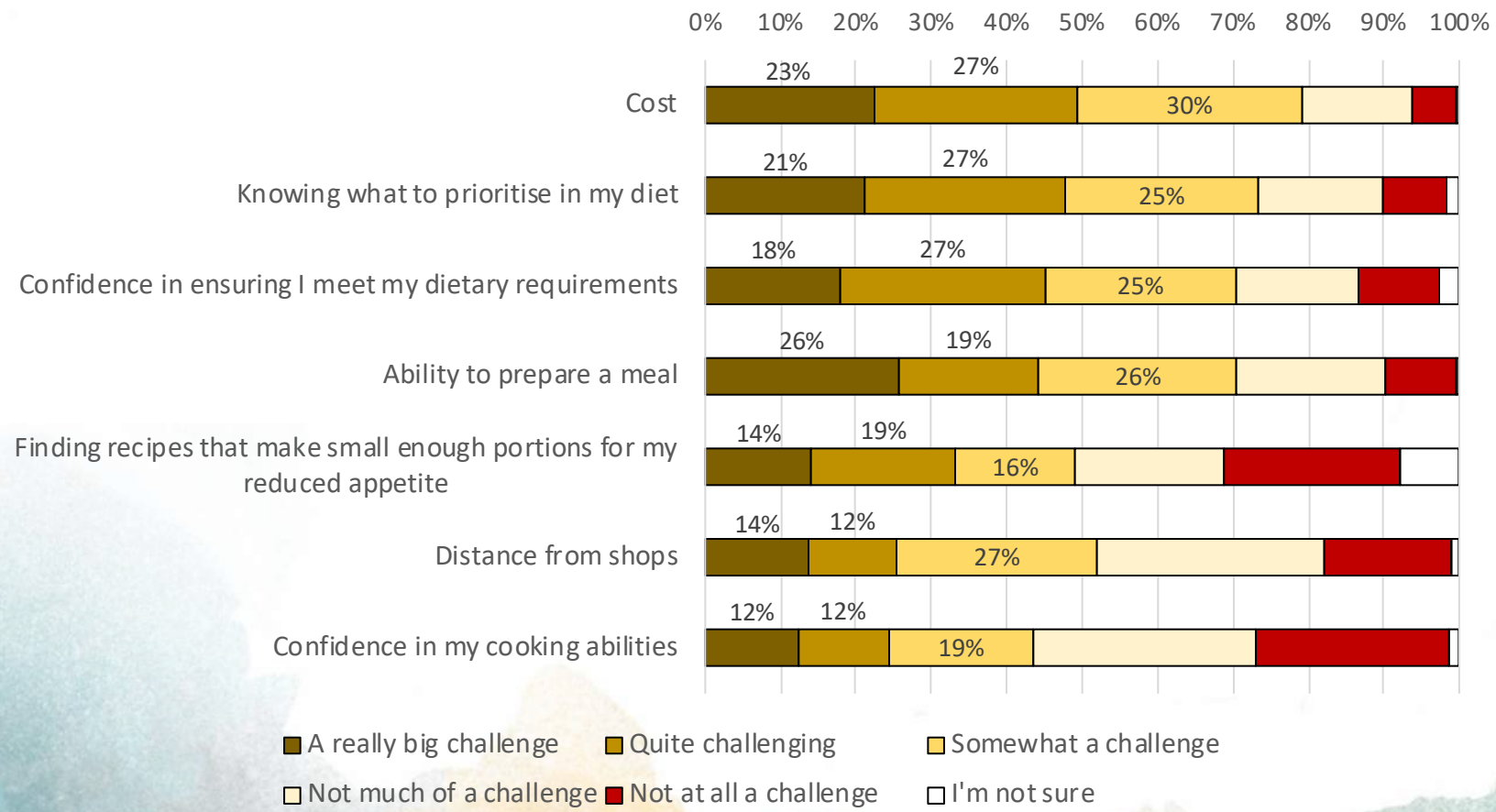


Question asked only of those who said an offering on food and nutrition would be very, quite or somewhat useful



Challenges of food and nutrition

What challenges do you face in trying to eat better?
(284 responses)



Question asked only of those who said an offering on food and nutrition would be very, quite or somewhat useful



What resources, websites, social media accounts etc., do you already find useful in supporting good nutrition for yourself and/or someone with chronic illness?

tasty videos

None, I tend to stick to the foods I know.
I've found sugar/carb contents is rarely
correct on web

Pinterest

Fodmap website

NHS

Hello Fresh
Gousto

None

Facebook

YouTube

Instagram

BBC good food

Slimming World



Mental and emotional health and relationships

Needs of sufferers, current practices and demand for
Chronically Awesome support



Key findings

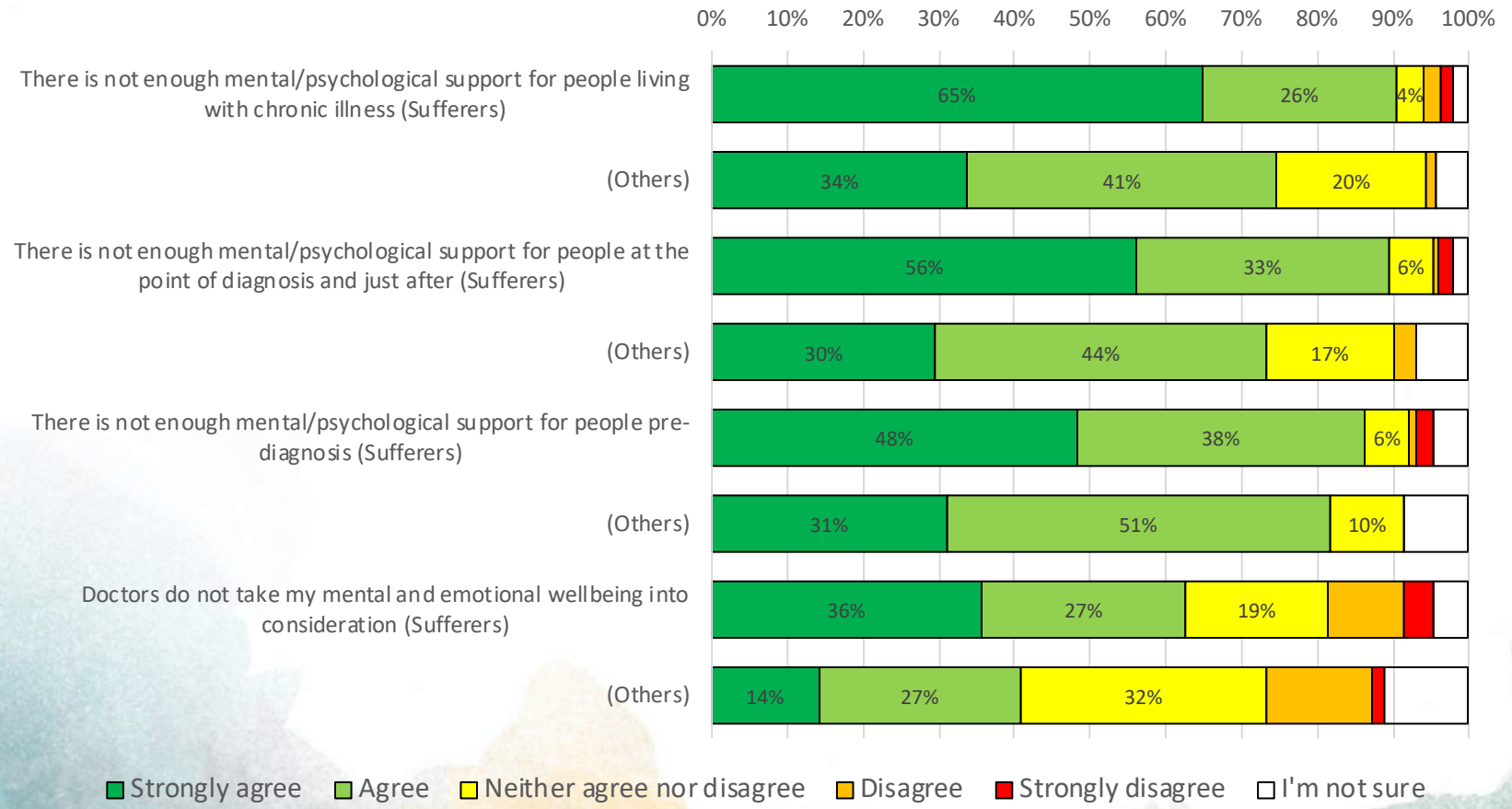
Mental and emotional health and relationships

- Almost all sufferers asked report that they feel that there is not enough mental and psychological support for people with chronic illness at all stages of diagnosis (pre-diagnosis, at the point or just after, and post-diagnosis)



Provision of mental and emotional health support

To what extent do you agree with the following (284 responses from sufferers; 71 responses from others)



Question asked only of those who said an offering on mental and emotional health and relationships would be very, quite or somewhat useful





Key findings

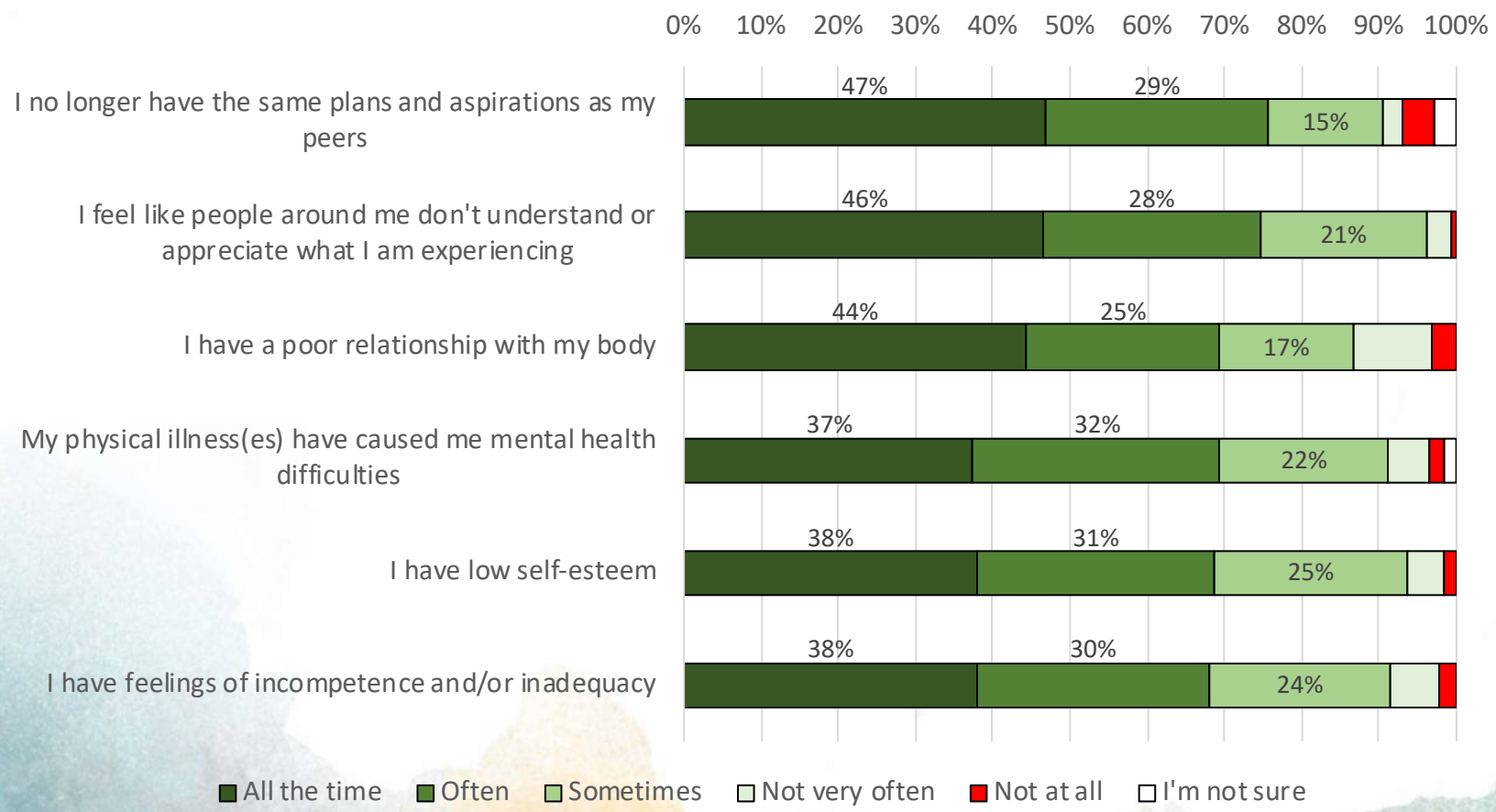
Impact on mental and emotional health and relationships

- More than three quarters of sufferers report that they no longer have the same plans and aspirations as their peers (all of the time or often).
- Almost three quarters report that they feel like people around them don't understand or appreciate what they are experiencing (all of the time or often).
- More than two thirds report that they have a poor relationship with their bodies and the same proportion report that their physical illness(es) have caused them mental health difficulties (all of the time or often).
- More than two thirds have low self-esteem, more than two thirds have feelings of incompetence and/or inadequacy and 63% feel that they will never amount to anything or achieve anything (all the time or often).
- 61% report feeling lonely and/or isolated (all the time or often).
- More than half of sufferers report struggling to maintain connection with friends and family. Similarly, more than half report not feeling that they can relate to anyone their age (all the time or often).
- 19% of sufferers report being stuck in a relationship due to being dependent on a partner.



Impact on mental and emotional health

How does your illness (or illnesses) and symptoms impact on your mental and emotional health? (284 responses)
(Part 1: Most common impacts)



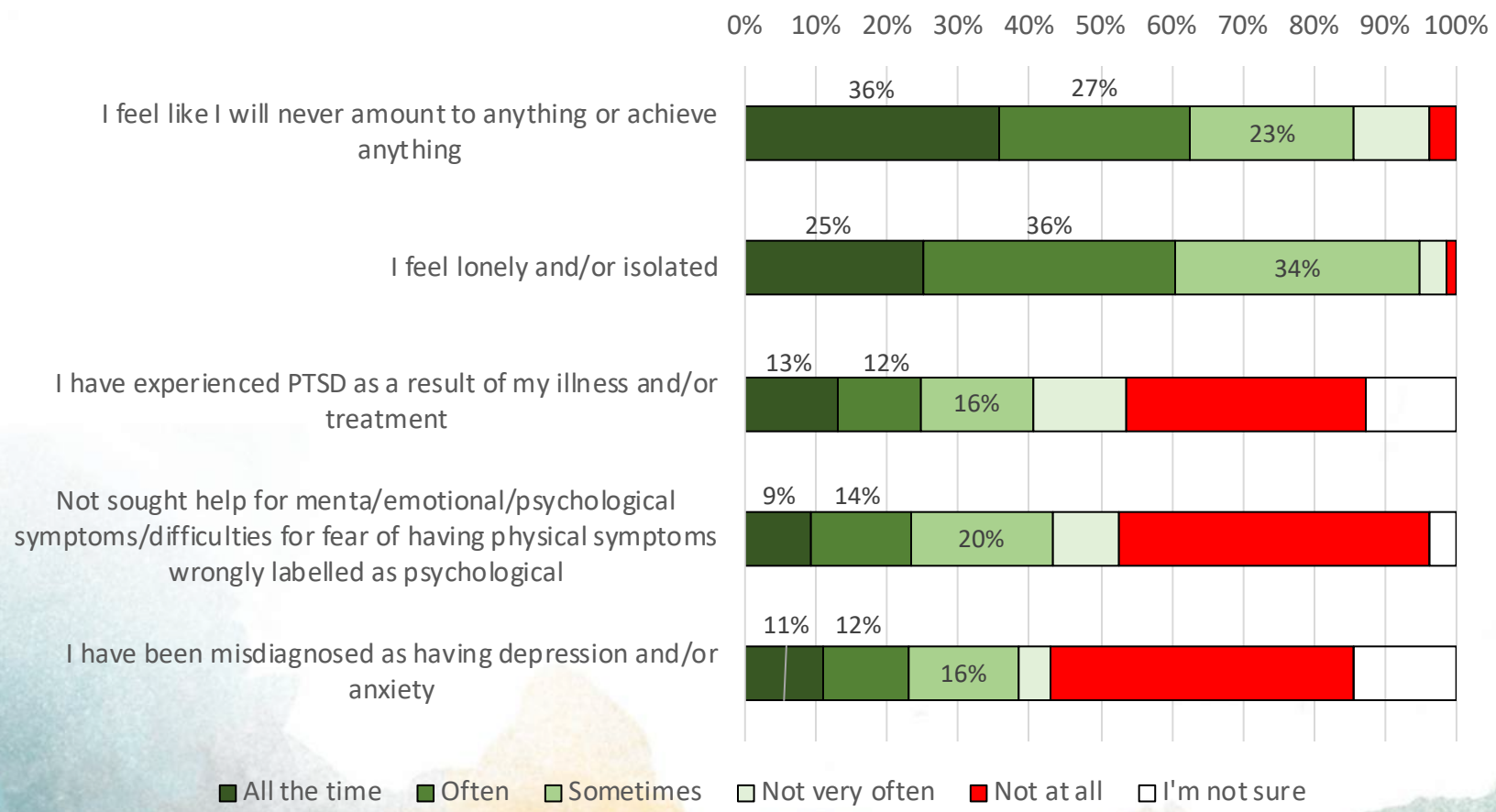
Question asked only of those who said an offering on mental and emotional health and relationships would be very, quite or somewhat useful





Impact on mental and emotional health

How does your illness (or illnesses) and symptoms impact on your mental and emotional health? (284 responses)
(Part 2: Other impacts)

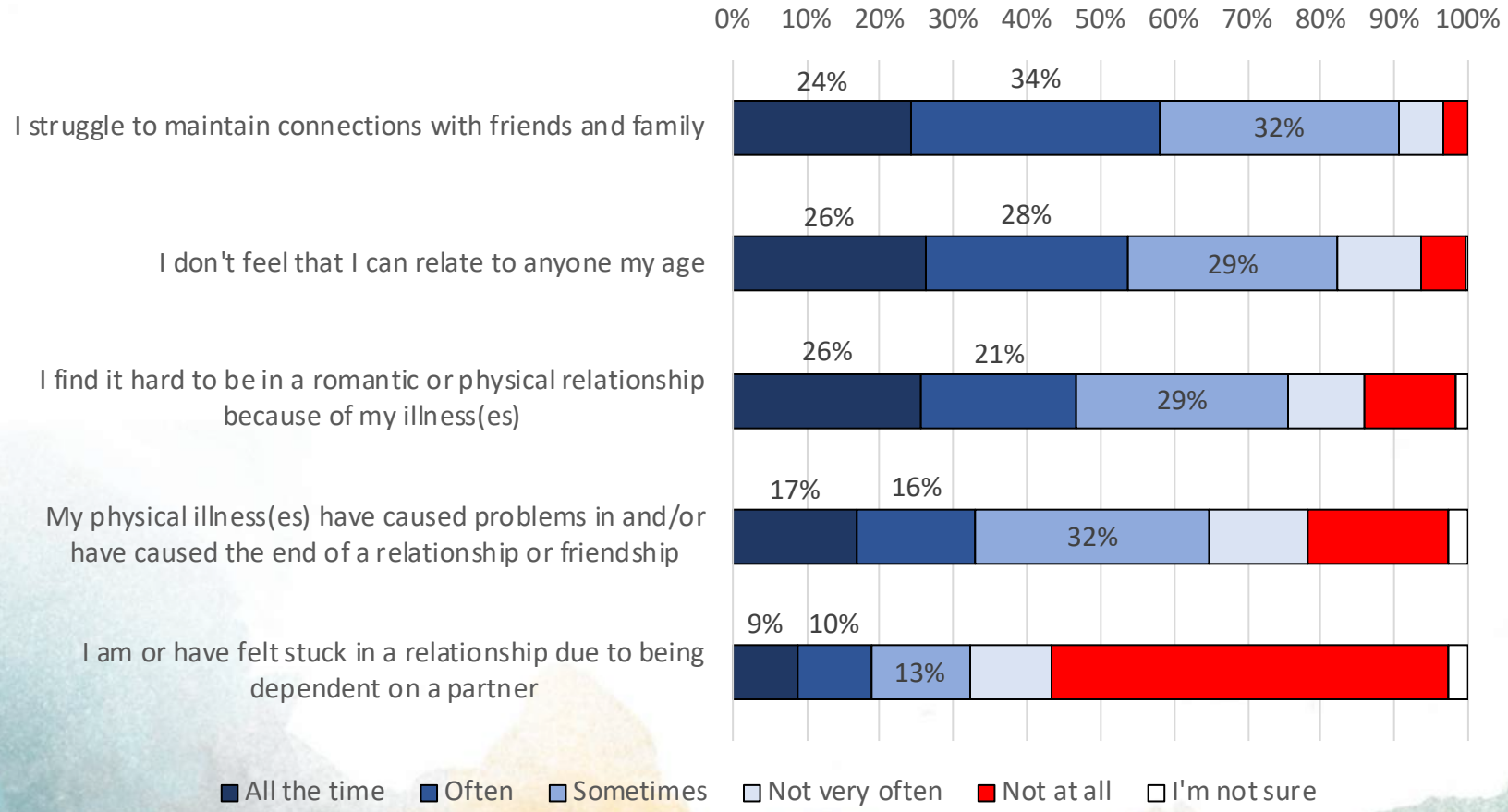


Question asked only of those who said an offering on mental and emotional health and relationships would be very, quite or somewhat useful



Impact on relationships and friendships

How does your illness (or illnesses) and symptoms impact on your relationships and friendships?
(284 responses)



Question asked only of those who said an offering on mental and emotional health and relationships would be very, quite or somewhat useful





Key findings

Mental and emotional health: what would be helpful

- There's clear demand for practical lessons, tips and coping mechanisms to help sufferers feel and be more resilient in mental and emotional health (76% report this) and in relationships and friendships (70% report this).
- There's a mixed picture about how this should be delivered, suggesting a need for Chronically Awesome to test out different approaches:
 - Most sufferers report that it would be helpful to get advice from qualified professionals, hear about personal experiences, and share candid experiences honestly;
 - Memes with words of inspiration, encouragement or humour and blogs are the most popular means of communication, compared with podcasts and video.
- Friends and family, colleagues and professionals are more positive than sufferers themselves about how useful support would be for feeling and being more resilient in their mental and emotional health and relationships, and are more positive about the usefulness of support around mental and emotional health than around relationships.
- There's also a mixed picture about how often people would like new content on mental and emotional health and relationships: More than a quarter of sufferers and others report wanting new content between once a month and once a week, 40% of sufferers and 28% of others report wanting new content once a week and a little less than a quarter of sufferers and others want new content several times a week.



What would help for mental and emotional health

What would help you to feel and be more resilient in your mentally and emotionally? (281 responses)



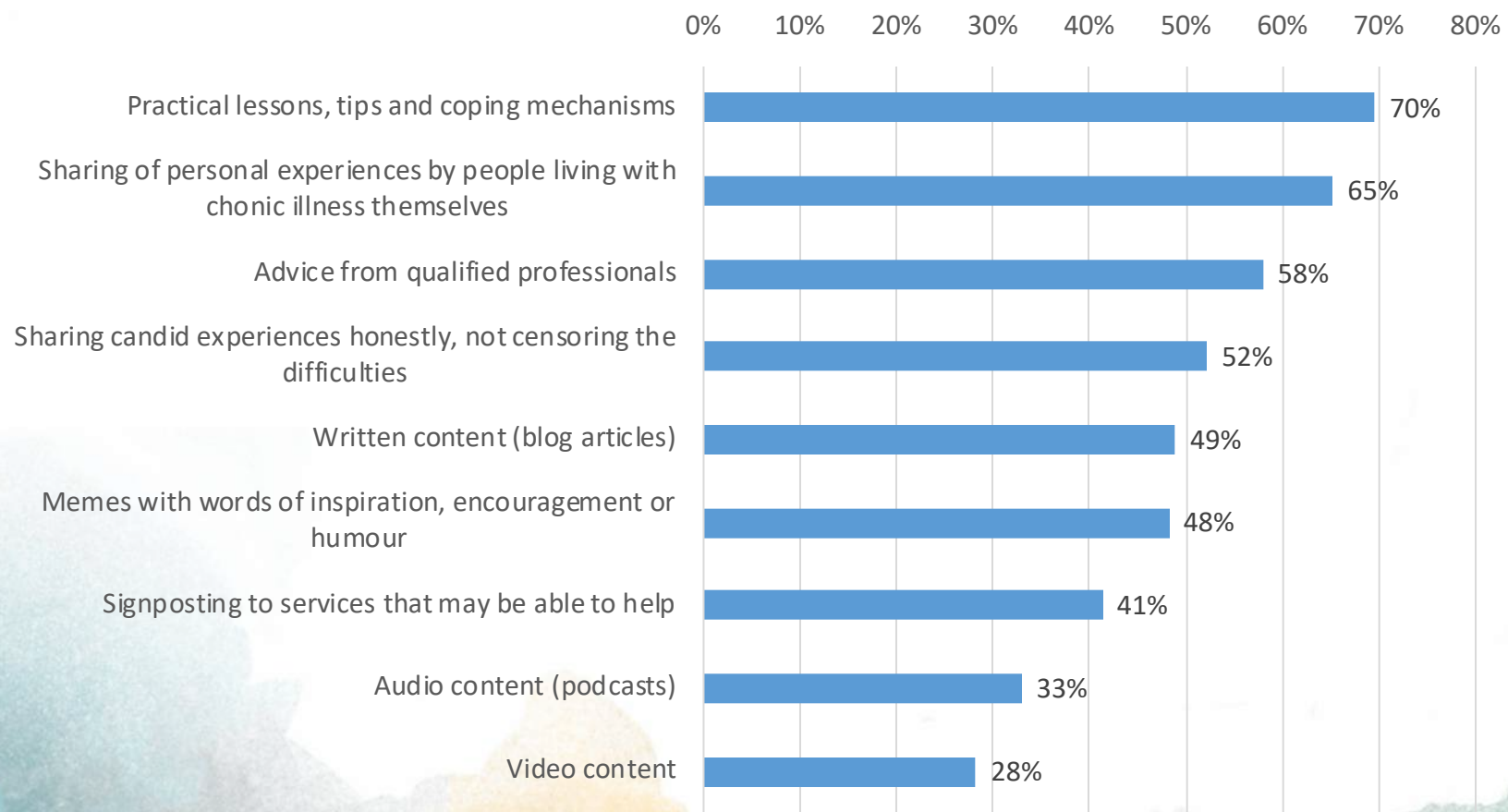
Question asked only of those who said an offering on mental and emotional health and relationships would be very, quite or somewhat useful





What would help for relationships and friendships

What would help you to feel and be more resilient in your relationships and friendships? (276 responses)



Question asked only of those who said an offering on mental and emotional health and relationships would be very, quite or somewhat useful





What organisations, services, websites, social media accounts and other resources do you already find useful in supporting good mental and emotional health and relationships for yourself and for people living with chronic illness?

I use the online support groups for my condition. They're great. They weren't around when I was first diagnosed and the general support from work/docs wasn't great, I find workplaces still aren't but they don't know about the condition. Its been a lot better since I discovered the online groups

NHS

Mind

Mind Restore

Calm App

Facebook

There's none

Twitter

Instagram

Local counselling (very expensive private). Talking to sufferers at hydrotherapy and special yoga

Samaritans

Youtube

Headspace

Charity Websites (e.g. chrohns & colitis UK)

Beat

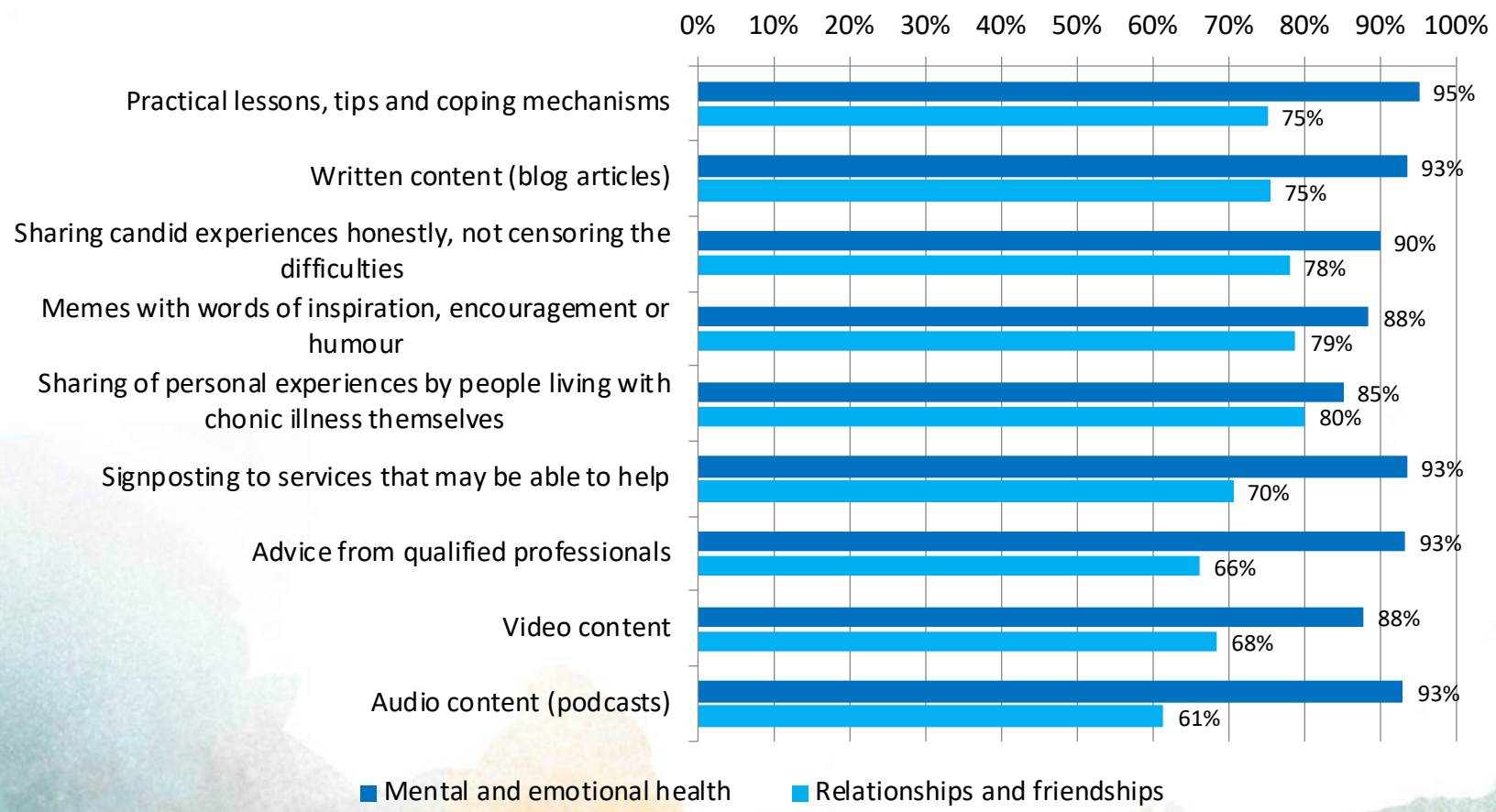
campaign against living miserable





What would help – view from others

What would help people living with chronic illness feel and be more resilient in the following areas? (Answers by 62 friends and family, colleagues and professionals)



Question asked only of those who said an offering on mental and emotional health and relationships would be very, quite or somewhat useful





Navigating work

Needs of sufferers, current practices and demand for
Chronically Awesome support



Key findings

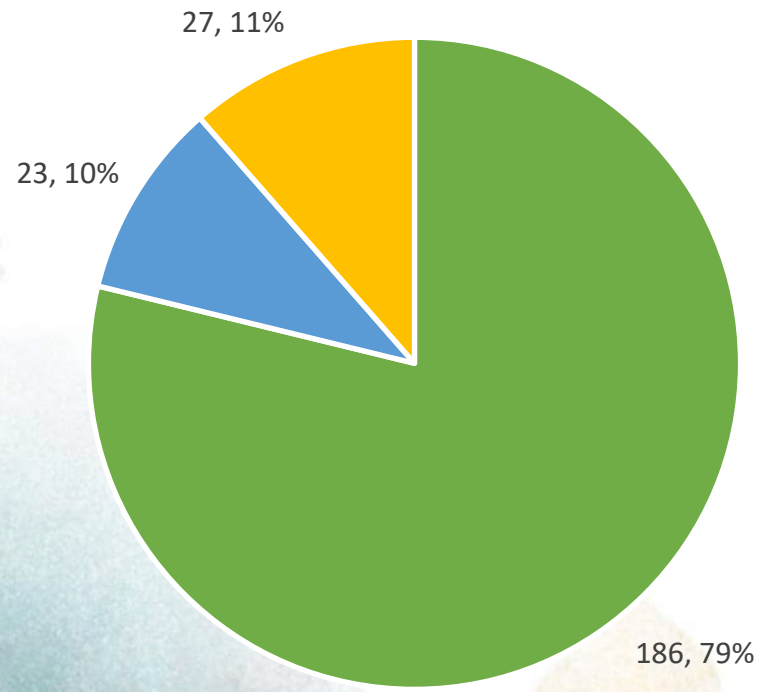
The need for support for navigating work

- More than three quarters of sufferers asked report that their chronic illness affect them in their work.
- 44% of sufferers asked report not being currently in work. 17% have a part time job. Only 15% of sufferers report having a full-time job.
- Almost half report not being able to take on as many hours as they would like.
- More than a third of sufferers have had to give up work entirely.
- More than a third are unable to pursue the job or career that they have trained for or wanted because of illness.
- 29% reporting being disadvantage in their job because of their illness and more than 20% feel discriminated against because of chronic illness.



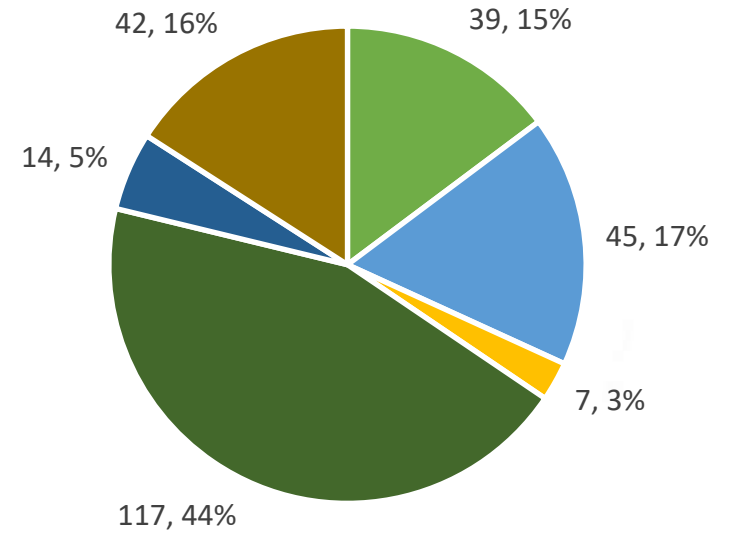
Experience of work of sufferers *(those who said an offering on navigating work would somewhat, quite and very useful)*

Does your chronic illness (or chronic illnesses) affect you in your work? (236)



Yes No I'm not sure

Are you currently in work? (235)

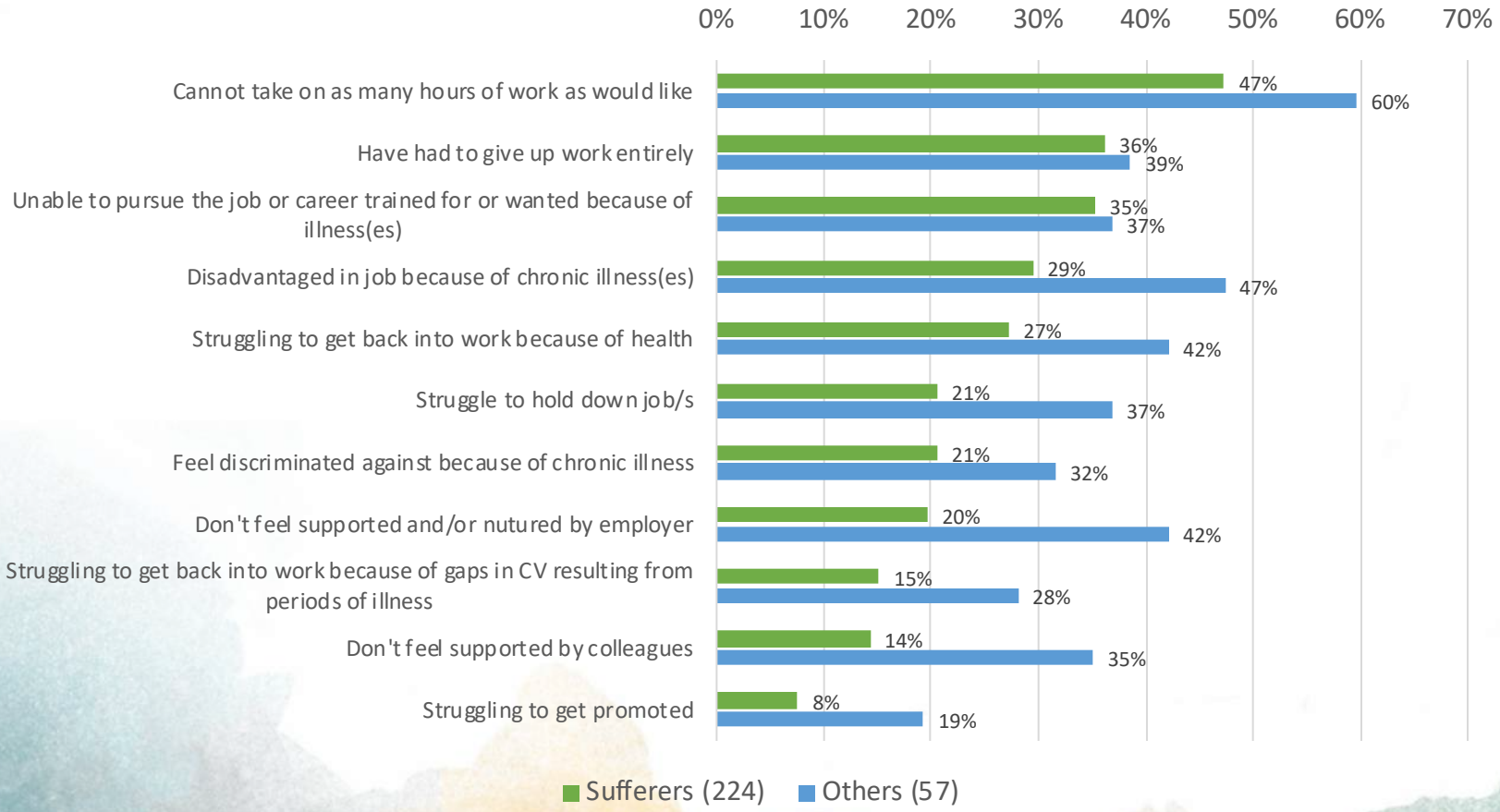


I have a full-time job
I have a part-time job
I have multiple part-time jobs
I am not currently in work
I am self-employed
Other



Challenges to navigating work

What challenges do people living with chronic illness you know face in trying to navigate work?



Question asked only of those who said an offering on navigating work would be very, quite or somewhat useful



What organisations, services, websites, social media accounts and other resources do you already find useful in supporting navigating work in people living with chronic illness?

A friend in an HR dept and then just searching online. Also the online support groups

Action for ME

Instagram

ACAS

Youtube

None this is very important and lacking content

Citizen's Advice



About this research

This research was conducted by
Chronically Awesome

Registered charity no. 1188337

www.chronicallyawesome.org.uk

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