



Survey Results:

Looking after your health with a long-term condition.

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Executive Summary

About the survey

This report shares the findings of a survey that the Health Care Consumers' Association (HCCA) conducted as part of the research project, *Looking after your health with a long-term condition*. The survey asked consumers who have one or more chronic condition, and people who care for them, about:

- How they look after their health
- People and services who help them to do this
- What makes it harder, and
- How COVID-19 has changed how they look after their health.

The survey had two parts, one for consumers, and one for carers. The questions for carers enquired about their role in supporting the person the care for to look after their health.

The aim of the survey was to identify changes that would improve information, support and care for people with long-term conditions who use health services in the ACT.

The survey ran from April to August 2020.

Participants

104 people with a wide range of chronic conditions completed the survey. Of the 104 respondents, 86 (or 82 per cent) answered as consumers and 18 participants (and 18 per cent) answered as carers.

The chronic conditions affecting the largest numbers of participants were arthritis, asthma, anxiety, depression, and pain.

While the survey respondents are diverse, more than half of all participants are women, aged 55 or over, who speak English at home.

Summary of findings

Self-management

The survey finds that most participants feel confident to look after their health, most of the time. A majority report that they are able to manage their symptoms (75 per cent), notice when their symptoms change (93 per cent) and know what to do when symptoms worsen (84 per cent). Most participants (98 per cent) seek out information about their health and how to look after it. A majority (82 per cent) keep copies of documents about their health (e.g. hospital discharge papers and test results). While

most find this manageable, almost a third (28 per cent) say this is time-consuming. Seven per cent need help from someone else to do this.

Almost all participants (95 per cent) know the names of their medications, and what they're for. More than three quarters (79 per cent) find it easy to take medication in the way a doctor or pharmacist has told them to. More than 9 in of every 10 participants (91 per cent) are used to taking medication, and think of it as part of their routine. The same proportion (91 per cent) find it easy to ask a doctor or a pharmacist a question about their medication.

Most (80 per cent) had made "a lot" of changes to their daily lives since being diagnosed. Over half (61 per cent) try to eat differently, more than three quarters (76 per cent) try to move more or get more exercise, 39 per cent drink less alcohol or smoke fewer cigarettes, 40 per cent conserve their energy, and 37 per cent have joined a peer organisation.

A majority (71 per cent) said that health professionals respect their opinions and knowledge about their health. Almost all participants (92 per cent) are involved in decisions about their care and treatment, and most (79 per cent) think that health professionals usually talk about risks and benefits in a way they can understand.

Just over half the respondents (54 per cent) find it easy, or very easy, to find good health information, while almost a third (27 per cent) find this difficult, or very difficult. (The remaining 19 per cent are unsure). While 61 per cent of participants report that their health professionals usually have up-to-date information about any changes to their health care, this leaves 20 per cent of respondents who say this is not the case, and 19 per cent who are unsure. Almost three quarters of participants (73 per cent) said they have had to tell their story many times to different health professionals. Of participants, 43 per cent say that the complexity of the health system makes it hard to look after their health.

Carers' experiences

Findings from the small carer sample are consistent with the findings from the consumer survey questions, and findings from interviews. Carers' responses indicate the important role these people play in supporting the people they care for to look after their health. The survey highlights the different ways in which carers seek to ensure the people they care for receive safe, high quality healthcare.¹ Most carer respondents (81 per cent) know what to do if the person they care for has worsening symptoms, and nearly nine in every ten respondents (87 per cent) know and where to get help if the person they care for needs it. Carer respondents (93 per cent) seek information about the condition the person they care for has, or help the person they care for to find this information. Almost nine in every 10 respondents (88 per cent) help the person they care for to ask questions and tell health professionals what is important to them. Eight in ten carer respondents (80 per cent) help the person they

care for to organise and keep copies of medical records. More than half (56 per cent) say it takes a lot of their time to keep these documents in order.

Almost half of the carer respondents (44 per cent) find it hard to get good health information. A quarter (25 per cent) feel they have too much information. Only half (50 per cent) feel that health professionals usually have up-to-date information about any changes to the health and care of the person they care for. More than eight in every ten participants (87 per cent) say they have had to tell their story many times to different health professionals.

Half of the carer respondents (50 per cent) believe that health professionals respect the opinion and knowledge of the person they care. Slightly more (56 per cent) believe that health professionals respect their opinion and knowledge. This leaves 44 per cent who feel either that health professionals do not respect their opinion and knowledge (25 per cent), or who are unsure (19 per cent).

More than half (68 per cent) say that health professionals involve the person they care for in decisions. Exactly half (50 per cent) think that the health system is complicated, and this makes it hard for the person they care for to look after their health.

More than nine out of every ten carer respondents (93 per cent) know the names of the medications the person they care for takes, and what they're for. Most (81 per cent) help the person they care for to take medication safely. Most (87 per cent) would also find it easy to ask a doctor or pharmacist a question about a medication, and a majority (81 per cent) help the person they care for to ask health professionals questions about medications. Carers identified the cost of medications as the single greatest challenge related to symptom management.

Opportunities for change

Carer and consumer respondents identified opportunities to improve support for self-management. Their priorities include:

- Easier access to information about health conditions, procedures, services, and questions to ask health professionals.
- Improved workplace understanding of chronic conditions, and support for employees
- Improved approaches to pain management
- Opportunities to seek advice and care from community-based, condition-specific clinics designed to support self-management
- Timely and affordable access to people qualified to give advice about diet and exercise changes appropriate for individual circumstances
- Better systems for timely sharing of accurate patient information (with consent) between health services and professionals treating the person

- Better coordination of repeat scripts between general practices and pharmacies
- Affordable access to health-promoting activities e.g. exercise classes
- More bulk-billing general practices
- Education and support for general practitioners and other health professionals to increase understanding of rare conditions

Carers also identified better access to respite care as a priority for change.

COVID-19

Survey results indicate that COVID-19 has had a significant impact on how consumers and carers look after their health.

Findings

More than eight in every ten consumer respondents (82 per cent) say they have made changes to how they look after their health because of COVID-19. The top three changes reported by consumers are: seeing less of family and friends (90 per cent), changing how they interact with friends and family (for example using the phone or internet to talk) (69 per cent), and only leaving home for essential tasks (64 per cent). These answers reflect the fact that people completed the survey between April and August, during which time stricter social distancing measures were in place.

Most consumer respondents are aware they have a higher risk of serious illness if they contract COVID-19 (79 per cent) Nearly two-thirds (69 per cent) are concerned about how COVID-19 could affect them (69 per cent). 44 per cent reported feeling anxious or worried more often than usual, and the same proportion were concerned about whether the health system could cope. This response reflects a high level of concern about COVID-19 during the time period in which the survey took place.

Close to a third of respondents had chosen to delay or cancel health appointments. Just over half of all consumer respondents (53 per cent) had used telehealth. Of these, 80 per cent had a positive experience.

Carers' experiences

Almost half of the carer respondents (47 per cent) said it has been harder to help the person they care for look after their health during COVID-19. Just under a third of carers (27 per cent) said the person they care for has had to make a lot of changes during COVID-19. The three most reported changes were: seeing less of family and friends (93 per cent), exercising less (71 per cent) and interacting with family and friends in new ways, for example phone or internet (64 per cent). More than half (64 per cent) said they had done things to reduce the chance of catching the virus, for example cleaning surfaces more often or asking visitors to wash their hands.

Most carers (80 per cent) are aware the person they care for has a higher risk of serious illness if they get COVID-19 (80 per cent). Almost half (47 per cent) felt worried or anxious more often, and 40 per cent said the person they care for is worried or anxious more often.

More than half of the respondents (67 per cent) feel they can take the action they want to protect the health of the person they care for. Twenty per cent of carers do not think they can take action to protect the health of the person they care for during COVID-19, and the remainder (13) are unsure.

Almost a third (31 per cent) have deferred or cancelled a health appointment or procedure.

Most (92 per cent) have been offered a telehealth consultation, and many (69 per cent) have used telehealth. Of those, 67 per cent felt it was good or very good.

Conclusions

The survey findings indicate that most respondents undertake the many tasks and activities involved in self-managing their health with confidence, most of the time. A clear majority are positive about their relationship with health professionals and the extent to which health professionals support their involvement in decision-making. However, the survey responses also indicate that there is significant scope to improve health information for consumers and carers, and to improve information-sharing between health professionals and services. Out of pocket costs are a significant challenge for self-management. This issue was raised in relation to the cost of health appointments, procedures and medication costs.

Responses from a small number of carer respondents illustrate the important role carers play in supporting the people they care for to look after their health. The survey responses highlight the many ways in which carers seek to ensure safe, high quality healthcare for the people they care for.² Carer respondents identified the cost of medications as a significant barrier to self-management, and identified access to respite care as a priority for improvement.

COVID-19 has added to the existing demands of self-management, when you have a long-term condition or care for someone who does. While most respondents have been able to manage these new demands, for some this has added to an already considerable burden. That a minority of participants reported seeking help from a new mental health service or community organisation during COVID-19 is an illustration of this. Consistent with findings from interviews, the survey results indicate that telehealth has been a great support for self-management during COVID-19, with a high proportion of respondents using telehealth with a high degree of satisfaction.

Survey Results

About the survey

The Health Care Consumers' Association conducted a survey for consumers and carers as part of the research project, *Looking after your health with a long-term condition*. The survey ran between April and August 2020.

People were able to participate if:

- They have been diagnosed with one or more than one chronic condition and use health services in the ACT, or
- They care for someone who has one or more than one chronic condition and who uses health services in the ACT.

There were two parts to the survey, one for consumers and one for carers. The questions for carers asked about their role in supporting the person they care for to look after their health. It was possible for people to respond to both parts of the survey, that is, to answer both as a consumer, and as a carer.

For the purposes of the survey, a chronic condition was defined as any health condition that is expected to last for a year or longer, and means you need ongoing medical care (for example, taking a prescription medication or seeing a doctor regularly).

The survey asked about:

- How people look after their health
- People and services who help them to do this
- What makes it harder, and
- How COVID-19 has changed how they look after their health.

The aim of the survey is to identify changes that would improve information, support and care for people with long-term conditions who use health services in the ACT.

Promotion

HCCA promoted the opportunity to participate in the survey to our individual and organisational members. The invitation to participate was shared by email with HCCA members, on the HCCA Facebook page and in the fortnightly e-newsletter *Consumer Bites*.

HCCA also shared the invitation to participate with consumer organisations, health services and ACT Government agencies, who promoted the opportunity to their networks.

These organisations are:

ACT Council of Social Service (ACTCOSS)	Carers ACT
ACT ME/CFS Society	Epilepsy ACT
ACT Office for Mental Health and Wellbeing	Hepatitis ACT
Arthritis ACT	Mental Health Consumer Network
Canberra Alliance for Harm Minimisation and Advocacy	Meridian (formerly AIDS Action Council)
Canberra and Queanbeyan ADD Support Group (ADDACT)	Parkinson's ACT
Canberra Health Services, Chronic Disease Management Unit and Chronic Care Program	People with Disability ACT
Canberra Lung Life Support Group	RSI and Overuse Association ACT
	SHOUT ACT (Self Help Organisations United Together)
	Toora Women
	Women With Disabilities ACT

Participants

There were 104 participants in the survey. Of these, a majority answered the questions for consumers (86 people or 82 per cent), while 18 people (and 18 per cent) answered the questions for carers. An additional twenty-three per cent of people who completed the questions for consumers also care for a family member.

Consumer participants

Respondents have a wide range of conditions. The most common conditions for consumer participants were:

- Arthritis (affecting 46 per cent of participants)
- Asthma (affecting 32 per cent of participants),
- Pain (affecting 48 per cent of participants), including back pain (affecting 24 per cent of participants)
- Depression (affecting 27.5 per cent of participants)
- Anxiety (affecting 25 per cent of participants).

The list below details all the conditions that affect people who completed the questions for consumers.

Condition	Proportion of participants with this condition
Arthritis	46 per cent
Asthma	32 per cent
Anxiety	25 per cent
Back pain	24 per cent
Chronic Obstructive Pulmonary Disease	11 per cent
Coronary heart disease	4 per cent
Cardiovascular disease	14 per cent
Cancer	12 per cent
Depression	27.5 per cent
Kidney disease	2.5 per cent
Mental health condition (other than anxiety or depression)	10 per cent
Pain (other than back pain)	24 per cent
Other condition	45 per cent

Nearly half of the participants (45 per cent) had other conditions. These are:

- Adenomyosis
- Asbestosis
- Attention deficit hyperactivity disorder
- Bronchiectasis and GORD
- CFS
- Chronic reflux
- Complications from influenza A
- Ehlers Danlos Syndrome
- Endometriosis
- Fibromyalgia
- Glaucoma
- Histamine intolerance
- HIV
- Hormone and pituitary conditions
- Hypertension
- Inflammatory bowel disease
- Joint inflammation
- Kidney transplant
- Liver disease associated with Hepatitis C
- Lymphoedema and lipoedema
- Mixed Connective Tissue Disorder
- Myalgic encephalomyelitis
- Myasthenia gravis
- Osteopenia
- Parkinson's Disease
- Postural Orthostatic

- | | | |
|------------------------------|--------------------------|-------------------|
| Tachycardia Syndrome | • Pulmonary hypertension | • Stroke |
| • Psoriatic Arthritis | • Urinary incontinence | • Stroke deficits |
| • PTSD – Vietnam War Veteran | • Sleep apnoea | • Type 1 Diabetes |
| • Pulmonary fibrosis | • Spinal cord injuries | • Type 2 Diabetes |

Participants with more than one condition

Almost three quarters of participants (74 per cent) have more than one condition. In answer to the question, “If you have more than one condition, which of your conditions most affects you?”, participants said:

Currently, ADHD

Currently, the anxiety

Psoriatic arthritis

Asthma, marginally

Stroke

Pain

Arthritis at this time, as I am currently in remission

Depression, exacerbated by the physical limitations caused by the back damage and arthritis

Currently bronchiectasis. Previously it was osteoarthritis, but I had both knees replaced and a shoulder reconstruction some years ago. Before that, it was my heart that affected me the most, but I had a triple by-pass in the early 1990s and haven't looked back since.

Since Christmas, both conditions have been unstable

If untreated it would be depression, however as that is very well managed the condition that is having the worst impact is pain.

As these responses show, some respondents have a ‘primary’ condition that has the most impact on their lives. However many describe an interplay between the symptoms, and treatments, of their conditions, that makes it difficult to identify one conditions as ‘most important’. There can also be a difference between the condition that most affects day-to-day life, and the condition that is likely to have the most

significant long-term impact. For example one participant reported that pain is their most significant condition “day-to-day”, but hormone/pituitary conditions have the greater impact on their “long-term life expectancy”.

Time since diagnosis

A majority of participants had been diagnosed with their first condition many years ago. More than half (57 per cent) have lived with a long-term condition for 10 or more years. This suggests that many respondents can be considered ‘experienced’ self-managers of their health with a long-term condition.

Time since diagnosis	Percentage of participantsⁱ
More than twenty years	34 per cent
More than ten years ago	23 per cent
More than five years ago	22 per cent
More than three years ago	5 per cent
More than a year ago	12 per cent
In the last year	5 per cent

Life circumstances and demographic profile

While respondents have diverse life circumstances, more women aged 55 or over, and people who speak English at home, responded to the survey. More than 20 per cent of the people who completed the survey are carers. Although participants have one or more chronic health condition, slightly more than half describe their health as good, or excellent.

Some of the characteristics of the respondents are:

- 22 per cent of participants describe their health as excellent, 29 per cent as good, 21 per cent as fair, and 8 per cent as poor
- Half of all respondents are 55 or older.
 - 14 per cent are over 75
 - 36 per cent are aged 66-75
 - 15 per cent are 55-65
 - 21 per cent are 46-55
 - 23 per cent are 35-45
 - 3 per cent are 26-35
- 76 per cent participants are women, 23 per cent are men and one participant identified as non-binary.

ⁱ Total is 101 per cent due to rounding

- 23 per cent of respondents care for a person with a chronic condition or disability.
- 11 per cent speak a language other than English at home.

As this data indicates, there are some people who are under-represented among respondents. The survey was limited to adults aged over 18 and does not include perspectives from children or young people. No young adults (18-25) participated, and only 3 per cent of respondents were aged 26-35. Most respondents (50 per cent) are aged 55 or over. Men are underrepresented in the group. People of culturally and linguistically diverse backgrounds are under-represented in the sample (at 11 per cent of the survey respondents compared to just over 30 per cent of the ACT population). One Aboriginal or Torres Strait Islander person participated. The experiences of people from these communities should be studied separately.

Carer participants

Health conditions

Eighteen people (or 18 per cent of respondents) answered the questions for carers. The people they care for have a range of long-term conditions, detailed in the list below.

- Arthritis (17 per cent)
- Asperger's Syndrome
- Asthma (6 per cent)
- Autism
- Back pain (22 per cent)
- Cancer (11 per cent)
- Cone dystrophy
- Dementia (17 per cent)
- Depression (39 per cent)
- Diabetes (22 per cent)
- Kidney disease (11 per cent)
- Mental health condition (not anxiety or depression) (28 per cent)
- Osteoporotic spinal fractures
- Pain (other than back pain) (17 per cent)
- Parkinson's Disease
- Post-concussion syndrome
- Progressive Supranuclear Palsy
- Sarcoidosis of the lungs
- Schizophrenia
- Sjogren's Syndrome
- Stiff Person Syndrome

Nearly three quarters (72 per cent) care for people with two or more conditions. Similar to the responses from consumer participants, some respondents care for people who have a clear 'primary' condition that affects them most, while others have conditions that are interwoven making it very difficult to identify which condition most affects them.

A combination of PTSD, anxiety, depression, schizophrenia plus incomplete paraplegic

Severe anxiety and cognitive issues

His pain and his dementia

Time since diagnosis

Most of the carer respondents (70 per cent) care for a person diagnosed more than five years ago.

- 12 per cent were diagnosed more than 20 years ago
- 24 per cent were diagnosed more than 10 years ago
- 25 per cent were diagnosed more than 5 years ago
- 24 per cent were diagnosed more than 3 years ago
- 6 per cent were diagnosed more than a year ago.

Findings

Managing symptoms

Most consumer respondents manage their symptoms (75 per cent), notice when their symptoms change (93 per cent) and know what to do when symptoms worsen (84 per cent). This is a key finding that indicates most respondents feel confident in their ability to look after this aspect of their health.

Respondents identified several challenges for symptom management, and opportunities to improve support in this area. These are detailed below.

Challenges

Some respondents find their symptoms very difficult to manage. The pain, fatigue and 'brain fog' that are symptomatic of many conditions can interfere significantly with daily life and make it hard to look after your health. Respondents said their symptoms can be a barrier to getting treatment and care when they need it.

The self-isolating response when depression is bad makes it hard to seek help, and depression impacts my sense of hope that would enable me to take positive steps about changing things I can.

It can also be difficult to notice deterioration in your health if symptoms incrementally worsen over time. Some respondents do not have 'typical' symptoms, which can make it harder to notice when symptoms worsen. And some conditions are characterised by sudden and unpredictable onset of acute symptoms.

Have not yet identified any measures to intervene after noticing signs of an attack. It is inevitable once it starts, which prompts significant anxiety

Participants report that it can be hard to tell if changes in health are caused by a chronic condition, or not.

Not knowing if it is associated with hepatitis or because of something else, like menopause [is difficult].

Respondents with multiple conditions said it can be hard to tell which condition might be causing a change in their health.

My condition changes quickly and not just day to day but sometimes minute to minute... I can get new and interesting symptoms daily or more often and sometimes it's hard to know when it's something serious or if it just part of one or more of conditions.

Medication to treat symptoms can have side-effects that must also be carefully managed. These two participants describe the challenges:

Taking strong pain meds impacts on the rest of life; not taking them means I have to cope with pain.

Important medication such as aromatase inhibitors worsen bone and joint pain, but you can't stop taking them.

One participant identified that it can take time to learn to use new self-monitoring technology.

Operating some of the new digital technology-based equipment being introduced to manage blood glucose levels.

Some participants with “invisible” health conditions – such as depression, anxiety, fibromyalgia and endometriosis – reported that limited community and health professional understanding of their conditions can make it much harder to manage their symptoms.

Medical practitioners who are ignorant about the condition or think it is psychosomatic [are challenging].

I have a largely invisible condition, unless I have my cane out or am in my chair, so there is a social pressure to pretend I do not have a condition, or a dismissal of my access needs because of the condition's variability.

All my conditions are made worse by anxiety, triggered by medical situations due to repeated dismissal of endometrioses issues.

It makes a very positive difference to participants, when health professionals have a good understanding of their condition, particularly when this is an “invisible” or stigmatised condition.

It is better when health professionals have a high awareness of Hepatitis C.

Opportunities for improvement

Participants identified changes they think would make it easier for them to manage their symptoms. These are:

Better up-front info on processes, locations, doctor's questions so I can prepare and feel less anxious.

More support in the workplace.

One point of access to multidisciplinary health advice and care including so-called non-mainstream treatments such as massage.

An accessible one-stop shop for pain management regardless of cause, or a multidisciplinary team approach for complex cases.

Community nurses accessible by everyone with a particular condition, not just those seeing a specialist at one public hospital.

More understanding and kindness from clinicians.

Carer experiences

Carers' responses indicate the important role they play in supporting symptom management. Just over half of the carer respondents (56 per cent) help the person they care for to monitor their symptoms. Most (81 per cent) know what to do if the person's symptoms worsen, and nearly nine in every ten respondents (87 per cent) knew and where to get help if the person they care for needs it.

Carers describe challenges including long wait times to see medical specialists for some conditions, and lack of medical specialists who can treat some conditions in the ACT:

Suitable support is not available at short notice. Access to paediatric specialists and psychological support for kids is difficult in the ACT.

Health professionals' lack of knowledge of rare conditions was also a barrier to symptom management.

PSP is a rare condition. There's no treatment for it, and little knowledge of it in the health sector and general community.

It is a poorly understood disease. Treatment is experimental. Psychological and physical symptoms cause each other.

Like consumer respondents, carers reported that the symptoms of some conditions can be a barrier to seeking care and treatment.

The person I care for doesn't want to engage with services.

They aren't motivated to adopt a healthier lifestyle. Lack of motivation is related to their mental health condition.

Mental health carers identified a lack of acute mental health services as a significant barrier to symptom management.

The person I care for can be quite unwell before I realise. Emergency care is really limited.

Carers' suggestions for improvements include:

Quieter mental health waiting rooms in services.

Education of health professionals especially GPs about rare conditions.

More affordable respite care options.

More health care services for people with acute mental health concerns.

Reliable respite (in our own home) so I can undergo surgery for big toe fusion.

One participant said that the lack of support and services for carers leaves them feeling that "there's not much anyone can do to improve things".

Getting and understanding health information

Most consumer participants (98 per cent) seek out information about their health and how to look after it. Just over half (54 per cent) find it easy, or very easy, to find good health information, however almost a third (27 per cent) find this difficult, or very difficult. 19 per cent per cent are unsure.

Some participants in interviews described experiencing “information overload”, but this is not a primary concern for most consumers who responded to the survey. A minority (21 per cent) feel they sometimes have too much information about their condition and their health.

More than half of the participants (61 per cent) report that their health professionals usually have up-to-date information about any changes to their health care. Twenty per cent of people said this was not usually the case. Nineteen per cent of respondents were unsure.

Almost three quarters of participants (73 per cent) said they have had to tell their story many times to different health professionals.

Challenges

The information-related challenges that participants identified include:

- Not being able to get information resources targeted for their life stage or circumstances – for example, one respondent said that resources about Attention Deficit Hyperactivity Disorder are almost always targeted toward children and parents, not recently-diagnosed adults.
- The quality of information about specific conditions varies - for example one respondent was able to “easily find information about one of my conditions, but it is rare to find information about all of them”.

Participants rely on health professionals as a key source of information. One of the most significant information-related challenges for participants is not being to see health professionals in a timely way, to seek advice and information.

There’s not always time with my GP, and it can be hard to see the same GP – if they work part-time or if they are a popular GP in the practice.

Respondents also identified the scarcity of specialist medical professionals for some conditions in the ACT, particularly rare conditions, as an issue. Several participants reported long wait times to see specialists.

Finding the right health professional is an issue for people with Parkinson’s and it can be even harder for younger people as they face fighting to be referred to a neurologist or told it’s not possible to have Parkinson’s Disease as they are too young.

The cost of medical appointments was also a barrier to accessing information from health professionals, with many respondents citing high out-of-pocket costs as an issue.

Diagnostic overshadowing is another challenge reported by some respondents. This is primarily a barrier to treatment, but it also means people can't get the information they need about their condition and self-management. Two participants said that health professionals had overlooked their physical health issues, or mistaken them as symptomatic of their mental health condition or disability.

Having a mental health flag can lead to many health professionals not taking physical health concerns seriously. The doctor treated me like I was crazy when I tried to get treatment for my knee.

For people with multiple conditions, it can be difficult to find health professionals who can consider the interactions of their conditions and treatments:

None of the health professionals I consult take a holistic approach to my care

Opportunities

Participants identified opportunities to improve information to support self-management. Their suggestions included:

Develop processes to seek patient input on brochures and other material, in public and private health care.

Produce more good quality and accurate handouts

Extend bulk-billing arrangements to allied health professionals

Carer experiences

Most carers who completed this survey (93 per cent) seek information about the condition of the person they care for, or help the person they care for to do this. Almost half (44 per cent) find it hard to find good information. A quarter (25 per cent) feel they have too much information. Half (50 per cent) feel that health professionals usually have up-to-date information about any changes to the health and care of the person they care for, while 31 per cent per cent find this is not usually the case (and 19 per cent are unsure). Almost nine in every 10 respondents (88 per cent) help the person they care for to ask questions and tell health professionals what is important to them. More than eight in ten participants (87 per cent) say they have had to tell their story many times to different health professionals.

Carers said that:

I have made a point of being informed about this condition, usually more informed than clinicians. This 'reverse health literacy' is embarrassing for my son as he thinks we should 'respect the doctor'.

There's a lot of information. It's hard to work out what applies to his unique circumstances.

There is shame and fear around complex health conditions – specialists just want to look at one thing.

It is a bit of a maze with this variety of dementia and how it affects individuals.

My father never tells the GP the truth and the GP never asks enough questions but getting a new GP would stress my father.

I get weary of searching and trying new things.

Carers' suggestions for improvement were:

More education for clinicians about rare conditions

Condition-specific nurses

Health coaching to help the person make diet and exercise changes

Managing documents and information

Most participants (82 per cent) keep copies of documents about their health (e.g. hospital discharge papers and test results). Most participants find this manageable. Almost all (93 per cent) do this themselves, without any help from someone else. It does take time to do this: almost a third (30 per cent) say it doesn't take them too much time, 28 per cent say it takes too much time, and 43 per cent are unsure.

Challenges

Some of the challenges for participants relate to their "lack of time to keep records in order" and "dislike of filing".

Filing is really boring so I only seem to fluke into the right mood to do my filing once a year (and never at tax time!)

Respondents also identified several challenges related to health services' systems for information management. These include:

- limited functionality in My Health Record
- difficulty accessing files held by health services or professionals, and
- difficulty sharing information (e.g. letters, test results) between treating health professionals.

My Health Record does not provide what it purports to do. I signed on and find it is not updated nor up to date.

I could populate My Health Record more effectively myself.

My paper records were lost in a transfer between care professionals.

Doctors and health professionals are often reluctant to give me copies of letters pertaining to visits to specialists or test results.

Some respondents find the quantity of health information they must manage almost overwhelming:

It is a massive novel, and no doctor really wants to look through it. I have also had to manage my treatment history across multiple countries, so I like to have everything in print.

The sheer volume of my records! I'm surprised I don't glow in the dark with all the x-rays and CT scans I've had.

One participant reporting finding it very difficult to make changes to their medical record:

I am fearful of attending any ACT medical service because they will write anything on your file. My records are loaded with errors, misquotes and diagnoses for conditions that have never been discussed with me, that I have never been treated for, or have been medicated for. For years I have been attempting to get my medical files corrected, and the system just said 'no'. Through the Human Rights Commission I can get the errors 'buried'.

Several respondents shared positive experiences of information management and information sharing. Below, two participants elaborate:

I know my GP has a copy of everything and he's happy to provide anything I need.

I really like that when you have a procedure in the public system, a hard copy of your discharge summary or images of your scans are provided to you on the day. Ten years ago, I didn't receive any documents after my procedures, and I feel this helps me understand the procedure and my health status.

Opportunities

Participants' suggestions for improvement are:

Health services should use consistent records systems and electronic communication.

Improve My Health Record.

Every health worker should make sure every record of an appointment or procedure is dated.

Better processes for communication between GPs and hospital-based professionals.

Easier, timely access for GPs to health information held by hospitals.

Carer perspectives

Eight in ten carer respondents (80 per cent) help the person they care for to organise and keep copies of medical records. More than half (56 per cent) say it takes a lot of their time to keep these documents in order.

Carer respondents suggested the following improvements:

More health services using the digital health record.

[It would be better if] hospitals kept records of tests and imaging

*[There was] access to all scans and test results across the whole ACT
system for all doctors and hospitals*

One carer respondent suggested carers would benefit from help to declutter and put in place sound record management

Medication

Almost all participants (95 per cent) know the names of their medications, and what they're for. More than three quarters (79 per cent) find it easy to take medication in the way a doctor or pharmacist has told them to. More than 9 out of every 10 participants (91 per cent) are used to taking medication and think of it as part of their routine. The same proportion (91 per cent) say they find it easy to ask a doctor or a pharmacist about their medication. More than half (67 per cent) have their medication reviewed regularly by a doctor or pharmacist.

Challenges

Respondents identified medication-related challenges including side effects, cost, having to have scripts renewed, and needing to ask for a medication review.

I can get the pharmacist to do a review, but I always forget to arrange it - memory loss is a major problem.

Scripts need renewing at different times.

Sometimes I get confused between generic and brand names of medications.

My medicine has side effects I don't like.

I resist taking them, they all have side effects.

Cost is always an issue, especially when you take multiple medications.

Participants appreciate the support of health professionals who involve them in decisions about medication use:

My specialist and I have a good relationship, he supports my input when we discuss my illness and treatment.

Several respondents would like a simpler process to renew prescriptions, when people have been on a medication long-term with a stable dose.

When you're on the same medication for a long time it's quite annoying to have to pay for a GP appointment to get a new prescription for something you need to be on forever.

Two participants identified better medication management in hospital as a priority.

During hospitalisation nurses do not adhere to the correct timing of the medication.

Opportunities

Participants think it would be easier to manage their medication if:

There was an equivalent to a Seniors' health Care for people with chronic conditions.

There was a national app linked to multiple pharmacies where you can choose to fill your scripts – you could select multiple pharmacies by location and compare prices or brand.

There was a lower limit on the PBS scheme that would allow lower prices on scripts.

Carer experiences

Carer responses indicate the important role carers play in helping people manage medications. More than nine out of every ten carer respondents (93 per cent) know the names of the medications the person they care for takes, and what they're for. 81 per cent help the person they care for to take medication safely. 87 per cent would find it easy to ask a doctor or pharmacist a question about a medication, and 81 per cent help the person they care for to ask health professionals questions about medications.

Carers identified the cost of medications as the single greatest challenge in this area.

Cost is a factor.

Our monthly pharmaceutical bill is around \$400 and that is with a concession care.

Medication is a huge percentage of our regular budget.

Carers identified changes that would help:

Inclusion of more medication on the PBS.

Better management of repeat scripts between doctors and pharmacies.

Better knowledge from hospital staff about the importance of timely and correct medications and the interactions of some meds in complex disease.

Interacting with health professionals

Many participants (71 per cent) said health professionals respect their opinions and knowledge about their health. Eight percent said this was not the case.

Almost all participants (92 per cent) are involved in decisions about care and treatment. Most (79 per cent) think that health professionals usually talk about risks and benefits in ways they can understand. Less than half (43 per cent) think the complexity of the health care system makes it hard to look after their health.

Challenges

The challenges for participants include:

- Difficulty finding health professionals they trust
- Wait times for consultations with GPs and medical specialists, and
- Unaffordable out-of-pocket costs.

I just need someone who understands me. It takes time to build trust with someone new.

There's always a long wait time to see my GP. I'm considering moving to another practice but appreciate that my current GP knows me.

Wait times can be ridiculous, I have been waiting to see a gastroenterologist for over two years.

My family is on a low income but not benefits, so I often think twice about going to the GP.

Opportunities

Participants identified the following opportunities to improve support in this area.

More bulk-billing General Practices in the ACT.

Greater access to affordable or bulk-billing allied health.

Government investment to reduce wait times for elective surgeries.

Improved communication between different health professionals and services involved a person's care.

Respondents would like to see:

More connection between your care team, longer appointment times, opportunities to see nurses instead of doctors if they are qualified enough.

Shorter wait times, the ability to see multiple specialists and have them talk to each other.

More allied health in Tuggeranong.

Increased access to bulk-billed allied health appointments.

More investment in getting elective surgeries done.

Carer experiences

Half of the carer respondents (50 per cent) believe that health professionals respect the opinion and knowledge of the person they care. Slightly more (56 per cent) believe that health professionals respect their opinion and knowledge.

More than half (68 per cent) say that health professionals involve the person they care for in decisions. Half (50 per cent) think that the complexity of the health system makes it hard for the person they care for to look after their health. More than half (69 per cent) think health professionals usually talk about risks and benefits of treatments in way they, and the person they care for, can understand.

One carer respondent reflected that:

Medical appointments are always rushed, and doctors frequently don't take time to make sure he [the person I care for] is genuinely involved and has the opportunity to understand and make informed choices.

Carer respondents identified some changes they think would help:

Access to interstate telehealth, with face-to-face nurse support

More fact sheets that we can refer to later

Services communicating with each other and keeping records of contact

Some cover for the over 65s for exercise therapies would help given the known benefits of staying active

Wider range of medications on PBS

More advocates and peers to help people

Changes to daily life

Many participants (80 per cent) had made “a lot” of changes to their daily lives since being diagnosed. Over half (61 per cent) try to eat differently, more than three quarters (76 per cent) try to move more or get more exercise, 39 per cent drink less alcohol or smoke fewer cigarettes, 40 per cent try to conserve their energy, and 37 per cent have joined a peer organisation

Respondents described other changes to their daily lives, too. These include:

Left the workforce to look after my health.

Stopped doing so many recreational drugs.

I now do what I can, and the rest just has to wait.

Try to be more intentional about regular contact with a small group of friends, since that's hard for me.

Don't isolate myself.

Have made home renovations especially bathroom. Still need grab rails and handrail out the back.

I have moved closer to my children.

I have to be much more careful about how I move.

I need to factor in down time.

Reduced exposure to stress.

Challenges

Respondents identified barriers to these changes. Consistent with findings from interviews, these include:

- Lack of affordable and appropriate facilities for exercise, for people with specific conditions or physical limitations
- Lack of support and advice about what movement and exercise is appropriate.

It is hard to exercise when you are breathless

Opportunities

Participants identified some changes they think would assist:

Coaching to support behaviour change.

Having access to services and people that can help with things like weight loss, eating better, exercising etc.

Heath rebate for participation in exercise classes.

Carer perspectives

Eight in ten respondents to the carer survey (80 per cent) said the person they care for has made changes to daily life since diagnosis. These include:

Stopped drinking alcohol as interferes with medications.

Less active, a side effect of illness and treatment.

Less able to work and study.

Limited energy.

She thinks and talks about medication and health issues all the time.

Totally dependent on assistance. Has stopped work, needs assistance to walk and most problematic, assistance with speech and communication.

Going from an independent person to one who is now dependent on me.

Loss of independence, but still trying to do some exercise and stay active and engaged in the community.

Carers identified that timely access to affordable psychological, allied health and nursing care would assist them, and the person they care for, to cope with the impacts of ill-health and make health-promoting changes in daily life:

An offer of psychological help would be good. Not just a throw-away line but a sincere offer of help that would not cost too much (as it currently does).

A community Parkinson's nurse for practical advice would help.

Better access to physio and occupational therapy support [would help].

COVID-19

Consumer experiences

More than eight in ten consumers (82 per cent) say they have made changes to how they look after their health during COVID-19. These changes include:

I have seen less of family and friends (90 per cent)

I have changed how I interact with friends and family (for example using the phone or internet to talk) (69 per cent)

I have only left home for essential tasks (64 per cent)

I've spoken with people they live with about what they can do to reduce their change of catching the virus (45 per cent)

I've exercised less (45 per cent)

I have learnt about how COVID-19 could affect me (41 per cent)

I've exercised differently, for example indoors (29 per cent)

I have not left home at all (7 per cent)

I have made changes to care and support, for example asking support workers to wash their hands or cancelling in-home care services (7 per cent)

Participants had also:

Put in place rules about how much news about COVID-19 gets watched, and turned off the TV to manage fatigue and anxiety.

Worked from home.

Ordered shopping on the internet, and got neighbours to shop for me.

Eaten out less – which is better for my health.

Been more intentional about seeking out contact with people on the internet.

Stocked up on essential and hard to secure items.

Become more aware of handwashing and always carry sanitizer with me.

Almost half of consumer respondents (47 per cent) say it has been harder to look after their health during COVID-19. A quarter (25 per cent) do not think so, while 30 per cent are unsure. Almost three-quarters (74 per cent) feel they can protect their health during COVID-19. Eleven per cent feel they cannot protect their health during COVID-19, while 14 per cent are unsure.

COVID-19's impacts on respondents include:

- Being aware of having a higher risk of serious illness if I get COVID-19 (79 per cent)
- Being concerned about how COVID-19 could affect me or people I care about (69 per cent)
- Being concerned about whether the health system can cope (44 per cent)
- Feeling anxious and worried more often (44 per cent)
- Difficulty getting essential household supplies and groceries (33 per cent)
- Having to limit health spending (20 per cent)
- Spending more time caring for people who live with me (18 per cent)
- Someone in my household has lost a job (8 per cent)
- I haven't been able to get my usual medications (8 per cent)

Three participants describe some of these impacts below.

I have to be so very careful of everything I touch and everything that comes into my home or into contact with me.

The isolation has had a serious effect on my mental health.

I was advised that asthma does not increase my risk, based on the evidence available. But the evidence is limited and not long-term, so I still feel unsure about my risk.

However, many participants described being able to cope readily with these changes.

I've remained the same anti-social hermit I was before!

At first it was good to have to stay home as we did a lot of gardening and cleaned up the garage and garden shed, but now I would like to get out and about more.

Frankly for an introvert who was blessed to have a job that could be done from home, COVID has been the best thing, as long as I and my loved ones remain healthy.

Close to a third of respondents had chosen to delay or cancel health appointments. These included:

- GP appointment (33 per cent)
- Medical specialist (32 per cent)
- Test or procedure (27 per cent)
- Allied health appointment (28 per cent)

Participation in other health-promoting activities was also affected. Almost half (45 per cent) said they participated in fewer peer support activities than usual, while 28 per cent participated in online or telephone peer support. Four per cent said they had used a mental health service they did not use before, while six per cent needed more or different support from community services.

Participants report that since COVID-19, health professionals have:

- Offered a telehealth consultation (76 per cent of respondents)
- Deferred or cancelled an appointment (30 per cent of respondents)
- Talked to them about COVID-19 (35 per cent of respondents)
- Told me a prescription medication may not be available (14 per cent of respondents)
- Prescribed an alternative medication (4 per cent of respondents)

Just over half of all participants (53 per cent) had used telehealth. Of these, just over half (51 per cent) felt this was a good (29 per cent) or very good (22 per cent) experience. Just four per cent felt this was a poor experience, with the remainder neutral on this point.

Reflecting on their use of health services during COVID-19, participants said:

I think I either haven't sought or haven't needed as much care. I'm probably more reluctant to seek care in this environment.

I miss not being able to show my GP my symptoms or have a physical examination.

When I go anywhere the staff are very careful of me, as well as themselves.

A medical procedure was cancelled, could have been an important diagnosis.

I've avoided going out of any health care because too many shops, businesses, services do not provide adequate protection from possible contamination.

I think telehealth has improved quality and safety.

Carer experiences

Almost half of the carer respondents (47 per cent) say that COVID-19 has made it harder to look after the health of the person they care for. Just under a third of carers (27 per cent) say the person they care for has had to make a lot of changes during COVID-19. Carers said the person they care for had made changes includes:

- Seeing less of family and friends (93 per cent)

- Exercising less (71 per cent)
- Interacting with family and friends in new ways, for example phone or internet (64 per cent)
- Doing things to reduce the chance of catching the virus, for example cleaning surfaces more often or asking visitors to wash their hands (64 per cent)

Just over a third had only left home for essential tasks (36 per cent), and just under a third had not left home at all for a period (29 per cent).

Carers said:

We practiced physical distancing from the very first.

He only goes out for medical appointments and tests. We started going to the chemist and having a coffee with a friend in the last week or so.

Carers said COVID-19's impacts have included

- I'm aware the person I care for has a higher risk of serious illness if they get COVID-19 (80 per cent of respondents)
- I'm worried or anxious more often (47 per cent of respondents)
- The person I care for is worried or anxious more often (40 per cent of respondents)
- I'm worried about whether the health system can cope (27 per cent of respondents)
- I've had trouble getting essential household supplies and groceries (27 per cent of respondents).

Participants reflected that:

It is harder for me to encourage the person I care for to exercise (walk) more since COVID-19 changed routines.

Isolation has led to lower mood for both of us.

More than half of the carer respondents (67 per cent) feel they can take the action they want to, to protect the health of the person they care for. Twenty per cent of carers do not think they can take action to protect the health of the person they care for during COVID-19.

The impact of COVID-19 has been highly variable, as the participant reflections below indicate.

Life is much the same though we now stay at home more.

It has put more of a burden on us both, with added anxiety given the potential risk for a vulnerable person and the worry about who would care for them were I to become ill as the carer.

Carers have chosen to delay or cancel appointments due to COVID-19. This includes appointments with a GP (38 per cent of respondents), medical specialist (31 per cent), or allied health professional (38 per cent). They had also chosen to delay a test or procedure (38 per cent).

Carers report an increase in use of mental health services due to COVID-19. Eight percent of respondents said the person they care for has used a new mental health service during COVID-19, while 15 per cent of carer respondents have themselves used a mental health service they did not use before.

46 per cent of respondents said the person they care for has participated in fewer peer support activities, while 31 per cent said the person they care for has participated in online or virtual peer support activities.

Since COVID-19, health professionals have:

- Offered a telehealth consultation (92 per cent of respondents)
- Deferred or cancelled an appointment or procedure (31 per cent of respondents)
- Talked to the carer, or the person they care for, about how COVID could affect them (28 per cent of respondents)
- Told them a usual prescription medication may not be available (16 per cent) and prescribed an alternative medication (8 per cent of respondents)

Many (69 per cent) have used telehealth. Of those, 67 per cent found this good or very good.

Carers suggested that support during COVID-19 could be improved by:

Policies to consider the safety of face-to-face appointments and how these could be facilitated in the COVID context for individuals who are not at increased risk.

Psychological support that is affordable.

Simpler English explanations of COVID-19.

Conclusion

The survey findings indicate that most respondents undertake the many tasks and activities involved in self-managing their health with confidence, most of the time. A clear majority are positive about their relationship with health professionals and the extent to which health professionals support their involvement in decision-making. However, the survey responses also indicate that there is significant scope to improve health information for consumers and carers, and to improve information-sharing between health professionals and services. For consumer and carer respondents, high out-of-pocket health care costs are one of the most significant barriers to self-management.

Responses from a small number of carer respondents illustrate the important role carers play in supporting the people they care for to look after their health. The survey highlights the many ways that carers seek to ensure the people they care for receive healthcare that is safe and high quality.³ This includes seeking information, supporting the person they care for to be involved in healthcare decisions, assisting the person they care for to manage medications, and knowing when and where to seek help if their symptoms escalate. Carer respondents identified the cost of medications as a significant barrier to self-management, and identified access to respite care as a priority for improvement.

COVID-19 has added to the existing demands of self-management, when you have a long-term condition or care for someone who does. While most respondents have been able to manage these new demands, for some this has added to an already considerable burden. That a minority of participants reported seeking help from a new mental health service or community organisation during COVID-19 is an illustration of this. Consistent with findings from interviews, the survey results indicate that telehealth has supported self-management during COVID-19, with many survey respondents using telehealth with a high degree of satisfaction.

References

¹ Merner, B, S Hill and M Taylor. 2019. "I'm trying to stop things before they happen": Carers' Contributions to Patient Safety in Hospitals. *Qualitative Health Research*. Volume 29, Issue 10. <https://doi.org/10.1177/1049732319841021>

² Merner, B. See Note 1.

³ Merner, B. See Note 1.