

THE STATE OF CARING IN THE ISLE OF MAN

2022-2023

State of Caring 2022

In 2018, Crossroads asked carers living in the Isle of Man to take part in a Carers Survey to help us understand the state of caring on Island.

In 2022, we carried out this survey again in partnership with the Department of Health and Social Care to determine the current state of caring.

About the research

A survey was carried out between September and November 2022, with respondents able to complete the survey online or in paper form.

Carers were asked to share their experiences and thoughts on caring to help us understand how we could help them on their caring journey.

A total of 566 carers responded to the survey. Of the respondents:

- 2% are aged 18-24, 7% are aged 25-34, 20% are aged 35-44, 21% are aged 45-54, 28% are aged 55-64, 16% are aged 65-74, 5% are aged 75-84, and 1% are aged 85 and over.
- 80% are female, 18% are male, and less than 1% identify as non-binary.
- 92.5% are White (Manx, English, Welsh, Scottish, Northern Irish, or British), 3% are White (Irish) and 2% are White from a different background. 0.4% are White and Black Caribbean, 0.4% are White and Black African, 0.4% are White and Asian and 0.3% are from a Mixed/Multiple ethnic background. 0.3% are Asian/Asian British (Chinese) and 0.7% are from a different ethnic group that was not listed.
- 66% are married or in a domestic partnership, 17% are single, 7% are divorced, 5% co-habit, 2% are widowed, and 1% are separated. 2% of carers who responded had a different marital status or preferred not to say.
- 44% live in the East of the Island, 19% live in the North of the Island, 18% live in the South of the Island, 12% live in the West of the Island, and 7% live centrally.
- 27% have childcare responsibilities for a non-disabled child under 18 years old.
- 23% have a disability themselves.
- 45% are currently in employment. Of those, 25% are in full time employment and 20% are in part time employment. 28% are retired, 11% are unable to work, and 5% are unemployed. 3% are in education.

- 3% have been caring for one year or less, 12% for 1-2 years, 20% for 3-4 years, 28% for 5-9 years, 15% for 10-14 years, 8% for 15-19 years, and 14% for 20 years or more.
- 78% care for one person, 14% care for two people, 4% care for three people, and 4% care for four people or more.
- 47% are a parent to the person they care for, 30% are a spouse or partner, 19% are a child, 3% are a sibling, 2% are a grandparent, 2% are a neighbour or friend, and 2% are another family member such as an aunt or cousin.
- 38% care for 100 hours or more each week, 5% for 80-99 hours, 7% for 60-79 hours, 12% for 40-59 hours, 15% for 20-39 hours, 14% for 10-19 hours, and 9% for 0-9 hours.
- 84% provide practical help to the person(s) they care for, 82% provide emotional support, and 79% help with arranging and/or coordinating care and support, medical appointments and other help.
- 73% live with the person(s) they care for.
- 34% cannot leave the person(s) they care for on their own, and 42% can only leave the person(s) they care for on their own some of the time.

As not all respondents completed every question in the survey, a number of the figures given in this report are based upon responses from fewer than 566 carers.

Table: the type of care being provided by carers

Type of care	Percentage
Practical help (e.g., cooking, cleaning, housework)	84%
Emotional support	82%
Arranging and/or coordinating care and support, medical appointments, and other help	79%
Helping with medication	71%
Helping with financial matters and/or paperwork	65%
Personal care (e.g., bathing, washing, dressing, using the toilet)	57%
Help with moving around (e.g., walking, getting in and out of bed)	48%
Other	12%

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Context

In the Isle of Man, thousands of carers provide unpaid care to a family member or friend whose health and wellbeing would suffer without their help.

A carer is defined as a person who provides unpaid care and support to a family member, friend, partner or neighbour. This could be due to illness, disability, frailty, a mental health issue or addiction or substance misuse problems. A carer can be a person of any age, from a child to an adult.

Caring in the Isle of Man

The 2021 Isle of Man Census Report states that 4,869 residents over the age of 10 years old are providing care or support to someone living with a long-term illness, condition, or disability.¹ This is almost a 40% increase on 2011 Census.

In addition to the Census, public surveys can also provide an insight into the number of carers on Island. For example, the 2019 Isle of Man Social Attitudes Survey stated 14% of people were providing unpaid care, which equates to approximately 11,750 people.² Additionally, in the 2018 Isle of Man Youth Survey, 16% of those who took part identified themselves as someone who provided extra help and care for another person.³

However, recorded figures from the Census and surveys do not fully reveal the true number of carers on Island, due to reasons such as carers not identifying themselves as such and age limitations (the Census does not record young carers under the age of 10). It was estimated in 2007 that the true number of carers was over 10,000, with this figure now likely to be much higher.⁴ The differences in estimates and figures, together with limited data, means we cannot fully understand the extent of caring on Island.

The Island Plan

The Island Plan is a document from the Isle of Man Government that sets out a vision of building a secure, vibrant and sustainable future for our Island. The plan details the Government's commitments and priorities for 2021-2026 and some longer term plans.

¹ Isle of Man Government (2021), 2021 Isle of Man Census Report

² Isle of Man Government (2019), Social Attitudes Survey 2019

³ Isle of Man Government (2018), 2018 Isle of Man Youth Survey

⁴ Isle of Man Government (2010), Carers Strategy 2007-2010

To work towards a more secure, vibrant and sustainable Island nation for all, the plan focuses on five interrelated priorities:

1. Building great communities
2. An Island of health and wellbeing
3. A strong and diverse economy
4. An environment we can be proud of
5. Outstanding lifelong learning and development opportunities for all

As part of the priority for an Island of health and wellbeing, the Department of Health and Social Care are leading the following objective:

Priority	Title	What	How	Why
An Island of health and wellbeing	Support available for carers	An accessible, accountable, and compassionate 'Right Care, Right Time, Right Place' health and care system which is there for people throughout their lives	Provide appropriate support for those who choose to care for others at home by evaluating and reviewing the value of carers in the community and deliver improvements as part of the Health and Care Transformation Programme	To provide greater support to home carers recognising the valuable contribution they make to society including reducing primary care requirements

Outcome: Home carers are provided with appropriate support to allow them to undertake their roles, including respite care

What this means: As a home carer I can balance my own needs whilst caring for others. As a home carer I have a network of support to fulfil my caring role, so I am supported and don't feel isolated

In a further update to the Island Plan published in January 2023, it is stated that a programme for a Carer Strategy and Young Carer Strategy is underway. To deliver this, Crossroads and the Department of Health and Social Care are delighted to be working in partnership on this programme.

Summary

Many carers find their health and wellbeing, social life and relationships with others are impacted by their caring role, and there can also be a significant financial impact on carers.

With an ageing population, the number of carers is increasing and more people are taking on caring responsibilities. This report will offer a glimpse into the current state of caring on Island and explain the huge impact caring can have on a person's health and wellbeing, and other areas of their life.

This State of Caring report forms part of that joint work, and together we will use the learnings from this report to produce a national strategy for carers and young carers.

Health and wellbeing

Caring can have an impact on a carer's physical, emotional, and mental health. This could be due to the physical elements of caring, limited opportunities to take a break, or the worry of looking after their loved ones.

Physical and mental health

14% of responding carers said their physical health was 'bad' or 'very bad'. 43% described their physical health as 'fair', which was the most common answer.

More carers described their mental health as bad than their physical health, with 18% saying their mental health was 'bad' or 'very bad'. 43% described their mental health as 'fair', which was the most common answer.

"Being a full time carer is physically and emotionally draining."

"My mental health has been severely compromised."

Following on from this question, we asked carers which aspects of their health and wellbeing they worried about the most, 77% saying they were worried about feeling stressed or anxious.

Three quarters of responding carers (75%) said they were worried about feeling tired, and 61% were worried about not having the time to prioritise their physical and mental health.

Over half of responding carers (53%) said they were worried about getting enough sleep and 52% said they were concerned about not being able to take a break.

38% of responding carers said they were worried about feeling depressed.

"Although my role as a carer can be physically demanding, I often find that trying to lift my wife's mental spirits is very difficult and upsetting."

"Physically tired. Mentally drained."

When asked whether their health had changed since becoming a carer, 82% of responding carers said their health had suffered (compared to 66% in 2018). Of those, nearly half (49%) said their health had suffered slightly and 33% said their health had suffered significantly.

Only 17% of responding carers said their health had not changed, and less than 1% said their health had improved.

75% 

Three quarters of responding carers are worried about feeling tired

Table: the aspects of health and wellbeing carers are most worried about

Aspect	Percentage
Feeling stressed or anxious	77%
Feeling tired	75%
Not having the time to prioritise my physical and mental health	61%
Getting enough sleep	53%
Being unable to take a break	52%
Impact on my relationships	42%
Getting enough exercise	41%
Feeling depressed	38%
Feeling lonely or isolated	37%
Getting health appointments when I need them	31%
Eating a balanced diet	30%
General health deterioration	28%
Feeling panicked	18%
Persistent physical injury caused by or exacerbated by caring, such as back strain	16%
Other	5%

Respite

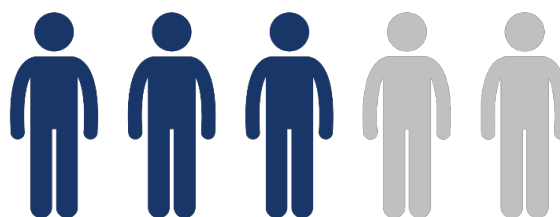
Carers were asked if they had taken a break from their caring role in the last 12 months, with 40% of responding carers stating they had been able to take a break.

Three in five responding carers (60%) said they had not taken a break, and of those, 33% said they hadn't tried to take a break because they thought it was too difficult. 14% said they had tried to take a break but hadn't been able to, and 13% said they did not feel like they needed a break.

Additionally, 17% of responding carers said that whilst they had been able to take a break, it wasn't long enough for them to look after their physical or mental health.

60%

Three fifths of responding carers have not taken a break in the last 12 months



Many carers commented that even when they did get a break, it was hard not to think about caring or the breaks they did have were not long enough to have a meaningful break.

“...even when we did manage to take a break it's still very difficult to disconnect.”

“Unable to take a meaningful break.”

“When I do take a break the preparation before going away, the worry something will go wrong while I am away, lack of support for the person I care for while I am away all make for a less than restful break.”

“It's difficult to adjust in a short time to not caring. Your mind is still occupied.”

Health professionals

37% of responding carers said they felt that health professionals did not take them seriously or understand their situation. This is an increase to the 2018 figure of 20%.

18% of responding carers said they did feel they were taken seriously and

were understood, and 45% said they only felt like this some of the time.

“I feel exhausted. I am constantly vigilant to my husband's health and being responsible for keeping him alive feels like a big weight to carry. I feel the health service do not consider who is caring for their person they are treating.”

42% of responding carers said their GP knew they were a carer, 28% said their GP did not know, and 30% said they were unsure.

Hospital discharge

We asked carers whether they had been through the hospital discharge process for the person(s) they care for in the last 12 months and if so, what their experience was like.

Of those who had experienced the hospital discharge process, over a third of responding carers (36%) agreed they were involved in decisions about the discharge. However, 44% disagreed with this.

Only 13% of responding carers agreed they were asked about their ability and willingness to care, whereas 72% disagreed that they had been asked

about this. 67% of responding carers disagreed that they felt they had been listened to about their ability and willingness to care with 12% saying agreeing they did feel listened to about this.

“Appointments and meetings are often scheduled at short notice during the working day. Conversations about discharge should have started on admission, just to allow the family to consider options and what the situation might be when parent was eventually discharged.”

Over two thirds of responding carers (68%) provided the opinion that they did not receive sufficient services to protect the health and wellbeing of the person(s) they cared for as well as their own health, compared to 10% agreeing with this.

“My job is my wife and I love her but on her discharge no one thought or asked about me.”

“My wife was discharged from hospital unable to get to the bathroom alone, unable to stand or walk unaided, unable to shower, to do anything for herself really and nothing was said about how she was going to manage at home. No care plan, no care at all.”

When asked to what extent they agreed that they were under no pressure to care and felt fully prepared and supported, 16% agreed with this, however 62% disagreed.

Quality of life

We asked carers to rate their quality of life choosing from the options ‘excellent’, ‘very good’, ‘good’, ‘sometimes good but sometimes poor’, ‘poor’, ‘very poor’, or ‘other’.

40% of responding carers said their life was ‘good’, ‘very good’ or ‘excellent’, 46% said it was ‘sometimes good or sometimes poor’, and 14% said it was ‘poor’ or ‘very poor’.

“I am a people person but not having the time to spend with people, has left me feeling very low and emotional and questioning what life holds for me.”

“There is no quality of my life just about providing a quality of life for our child.”

“I count myself lucky to have what I have. Others are in worse situations.”

“Caring is not especially difficult, but it is relentless.”

Additionally, when asked if they felt safe as a carer, 70% of responding carers said they did.

Table: how carers reported their quality of life

Aspect	Percentage
Excellent	3%
Very good	10%
Good	27%
Sometimes good but sometimes poor	46%
Poor	10%
Very poor	4%

Social impact of caring

Carers often miss out on socialising with others due to their caring responsibilities, especially if the person(s) they care for cannot be left on their own. Additionally, many carers report feelings of social isolation and loneliness, along with concerns about their futures.

Social life

We asked carers to describe their social life since becoming a carer.

84% of responding carers said their social life had suffered, with 57% of those stating it had suffered significantly. 14% of responding carers said their social life had not changed, and 2% said it had improved.

Nearly two thirds of responding carers (64%) said they felt or had felt they were missing out on aspects of their life. 27% of responding carers said they felt like they were missing out some of the time, and 9% said they did not feel like they were missing out.

Furthermore, when asked if they wished or had ever wished they could escape from their situation, 49% of responding carers said yes, 32% said sometimes and 19% said no.

Over a third of carers (38%) said they did not feel they had a life outside of

their caring role, and 40% said they only feel they do some of the time.

“We have no life outside of caring for our child. They cannot be left alone; we have no family to look after them to give us a break. It is relentless.”

“Feel I have become an unreliable and absent friend as cannot commit to activities/get togethers.”

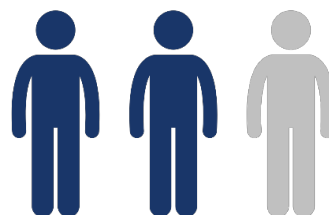
Carers were asked whether they expected that things would be different at this point in their life, with 71% of responding carers stating they did.

Loneliness and isolation

Carers were asked to tell us how often they felt lonely. 23% of responding carers said they felt lonely often or

64%

Nearly two thirds of responding carers have felt that they are missing out on aspects of their life



always and 48% said they felt lonely sometimes. 14% of responding carers said they hardly ever felt lonely and 10% said they never felt lonely.

Additionally, 81% of responding carers said they felt their relationships with others had been affected by their role as a carer, which can further increase feelings of loneliness.

“It can be very lonely because friends do not call as often as they did. I cannot go out without my partner, he does not like to be left.”

“Life as a carer is isolating. Only other carers can really understand the impact it has on your life and mental health.”

“I feel like I have lost my identity.”

When asked if there was anything that would help them to feel less lonely, 59% of responding carers said more understanding and recognition from society about the role of carers would help, and 53% said being able to take a regular break would help.

Other things responding carers said would help them feel less lonely would be access to emotional support services (44%), being able to take part in physical or leisure activities (31%) and being in contact with other carers (21%).

When asked if there were any other ideas that would help them feel less lonely, some responding carers said that more resources and funding could be beneficial.

“I feel lost and alone. I feel as my loved one deteriorates and things get harder there is less consideration towards your needs and more changes which are unsettling and upsetting.”

The future

Carers were also asked if they felt positive about their future, with 13% of responding carers stating they felt very positive about their future. 45% said they sometimes felt positive about their future.

Over a third of responding carers (35%) said they felt discouraged about their future, and 6% said they did not think things would work out for them in the future.

“I have learned to try not to think about the future because it is too frightening.”

“Worried and scared for the future.”

“I take life one day at a time and don't look to the future as that would make me cry!”

Financial impact of caring

Due to the additional expenses that come with caring, such as specialist equipment or transportation costs, many carers face financial struggles. This year, the cost-of-living crisis has increased financial difficulties for carers, with some no longer being able to afford essentials like food or heating.

Overview

Over two thirds of responding carers (69%) said they had been financially affected because of their caring role (a slight increase on the 2018 figure of 67%).

72% of responding carers said they were worried about living costs and whether they could manage in the future, and 27% of carers said they were struggling to make ends meet. One in five carers (20%) said they were in or had been in debt at some point because of caring. 18% said they were struggling to afford the cost of food, and 15% said they cannot afford utility bills like electricity, gas, and water or telephone bills. Only 13% of carers said they could afford their bills without struggling financially.

“Debt is a major concern, in 2018 I was 12k in debt, all this debt related to lack of money due to hospital appointments and UK treatments. Credit cards [are] maxed out.”

“The strain it puts on you... financially is a lot as you don't realise how much money it costs.”

“Worried about costs and future costs of care and if we can meet them.”

How carers are coping

We asked carers who were struggling to make ends meet how they were coping. 71% of carers said they were cutting back on luxuries, and 57% said they were cutting back on hobbies or leisure activities. Nearly half of carers (47%) said they were using their savings and 43% said they were cutting back on seeing friends and /or family members.

Worryingly, a third of carers (33%) said they were cutting back on essentials such as food and heating.

33%

A third of responding carers said they were cutting back on essentials such as food and heating



Table: how carers struggling to make ends meet said they were coping

Measure	Percentage
Cutting back on luxuries	71%
Cutting back on hobbies/leisure activities	57%
Using savings	47%
Cutting back on seeing friends/family	43%
Cutting back on essentials (like food and heating)	33%
Using my bank account overdraft	21%
Using credit cards	17%
Borrowing from family or friends	17%
Falling into arrears with utility bills	9%
Falling into arrears with housing costs i.e. rent or mortgage payments	7%
I am not coping	7%
Cutting back on support services which help with caring	6%
Taking out a loan from the bank	6%
Other	6%
Using food banks	4%
Using pay day loans	1%

“Our savings are being used up on care costs.”

“We used all of our savings.”

“It has had an adverse impact.”

“We had to get a second mortgage.”

“Carer's Allowance, DLA [Disability Living Allowance] and EPA [Employed Person's Allowance] are not enough to survive, especially now the cost of living is too high.”

Benefits

Only 33% of responding carers said they received Carer's Allowance, and 48% said they or the person(s) they cared for received Disability Living Allowance. 18% of responding carers said they received Attendance Allowance. Over a quarter of responding carers (26%) said they received no financial support from the benefits system.

The standard rate of Carer's Allowance in the Isle of Man for 2022/2023 was £140.35 per week, which was just over double the 2022/2023 standard rate in the UK of £69.70 per week.

In order to qualify for Carer's Allowance on Island, carers must

match the following basic qualifying conditions:

- Care for the disabled person for at least 35 hours per week
- Be aged 16 or over at the date of claim
- Not be earning more than the weekly earnings limit for Carer's Allowance
- Not be in education of more than 21 hours per week

When carers were asked what would help them with their caring role, nearly half of responding carers (49%) said more financial support would help, and 45% said more support from the social security system, for example a rise in Carer's Allowance, would help.

33%

Only a third of responding carers receive Carer's Allowance



Employment

Many carers juggle their caring role with employment which, for some, can be challenging with many saying they are tired, stressed and struggling to balance working with their caring responsibilities.

Overview

Three in five responding carers (61%) said their employment had been affected by their caring role.

“I have to constantly juggle between working from home and caring full time and get very tired.”

“Gave up job to care full time.”

“I took early retirement to become a fulltime carer.”

“Had to cut back hours and be more flexible with work patterns. Working from home more.”

“Less opportunities for promotion.”

Employers

71% of responding carers said their employer knew they were a carer, an improvement on the 2018 figure of 61%. Of those, 44% of responding carers said their employer allowed them to have flexible hours, 14% said they were not allowed flexible hours, and 13% said they choose not to have flexible hours.

13% of responding carers said their employer did not know they were a carer. 16% of responding carers said they were not sure if their employer knew they were a carer.



Three in five carers said their employment had been affected by their caring role

Juggling work and care

Carers were asked to indicate to what extent they agreed or disagreed with a number of statements about balancing work and care.

44% of responding carers either agreed (20%) or strongly agreed (24%) that working from home enabled them to balance work and care more effectively.

61% of responding carers said they agreed (37%) or strongly agreed (24%) that they were worried about continuing to juggle work and care.

55% of responding carers either agreed (34%) or strongly agreed (21%) that they felt anxious about caring whilst working.

61% of responding carers either agreed (27%) or strongly agreed (34%) that they had given up opportunities at work because of caring.

19% of responding carers either agreed (11%) or strongly agreed (8%) that their employer had introduced new measures since the Covid-19 pandemic which has helped them balance work and care. Nearly a third of responding carers (32%) said they disagreed (15%) or strongly disagreed (17%) with this.

17% of responding carers either agreed (10%) or strongly agreed (7%) that their employer had become much more understanding about caring since the pandemic. However, 30.5% of responding carers either disagreed (16.5%) or strongly disagreed (14%).

Over half (59%) of responding carers either agreed (33%) or strongly agreed (26%) that work gave them a break from their caring role. 8% disagreed and 1% strongly disagreed.

66% of responding carers either agreed (38%) or strongly agreed (28%) that they felt tired at work because of their caring role.

26% of responding carers said not being able to work from home would make them consider leaving their

employment, and 37% said that returning to the office would make caring more challenging for them.

What would help

When asked if there was anything that might help them to balance work and care, 43% of responding carers said the ability to take time off with paid Carer's Leave would help them. 32% of responding carers said links to good information and advice would help them to balance work and care, and a quarter of responding carers (25%) said they needed affordable and accessible and alternative care.

Positively, when asked if an understanding line manager or employer would help them to balance work and care, 45% of responding carers said they already had this at work. Additionally, more than a third of responding carers (34%) said flexible working was already something they were offered at work which helps them, and 30% said they had a peer support network which helps them.

Carer's assessments

A carer's assessment gives carers the opportunity to discuss how their caring role is impacting them and is designed to signpost carers to services and support.

Under the Social Services Act 2011, provision exists for carers to receive a carer assessment where the carer intends to provide another person with care on a regular basis.

Take up

Carers were asked if they knew they were entitled to a carer's assessment. 84% of responding carers said they did not know they were entitled to one.

We also asked carers whether they had received a carer's assessment in the last 12 months. 92% of responding carers said they had not had a carer's assessment. Of the carers who said they had received one, 7% waited less than 6 months to receive it, and 1% waited more than 6 months to receive it.

Barriers

Carers who had not received a carer's assessment in the last 12 months were asked what had stopped them from doing so. 74% of responding carers said they did not know what a carer's assessment was.

"I didn't know this was available and I don't have any information on how it might benefit me."

"I have never heard of a carer's assessment."

"I didn't know I could get one."

74%

Nearly three quarters of responding carers do not know what a carer's assessment is



Confusion with Carer's Allowance

From comments recorded by carers, there also appeared to be some confusion between carer's assessments and Carer's Allowance:

"I am not currently eligible as I have only lived on the island for 14 months. I believe there is a 2-3 year residency requirement before applying."

"I would lose other benefits."

"I worry that it might impact the benefits I already receive for my long term disability."

"I do not give the 35 hours care required."

The confusion between carer's assessments and Carer's Allowance indicates that more awareness is needed to ensure carers are receiving what they are entitled to and that they are accessing appropriate support.

Support and services

Many carers need practical and emotional support in order to provide care. Responding carers have told us that they are not getting the support they need, and in some cases are not aware of the support that is available to them.

Accessing services and support

Carers were asked if they were aware of what services and support were available to them. Nearly two thirds of responding carers (63%) said they were not aware of what is available to them. 31% of responding carers said they were aware of some of the services that were available, and 6% said they were aware of what was available.

When asked about how they found out about what services and support were available to them, common answers from carers included through their social worker, from Crossroads, through the hospital discharge process, the Department of Health and Social Care, through education, from their own research, other third sector organisations, and word of mouth.

We also provided carers with a list of services and asked them which ones they were currently accessing. 26% of responding carers are currently accessing activities and support from a local charity, and 16% from a local carers' organisation.

23% of responding carers are accessing day services and nearly one fifth (18%) are getting support from paid care workers. 4% of carers are accessing residential care, and 14% are using care homes for short respite breaks.

36% are accessing services not provided on the list, with some saying they weren't accessing any services at all.

We also asked carers whether they felt the services they did have access to were meeting their needs. 64% of responding carers said they did not. Many carers felt there was not enough flexibility in services and that there were not enough options available.

63%

Nearly two thirds of responding carers said they were not aware of what support was available to them

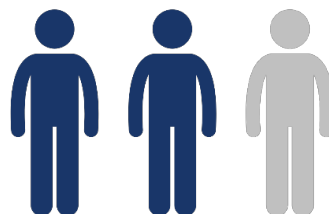


Table: which services carers are currently using

Service	Percentage
Activities and support provided by a local charity	26%
Day services	23%
Support from paid care workers	18%
Activities provided by local carers' organisation	16%
Care homes for short respite breaks	14%
Government funded care	7%
After-school services for disabled children and young people	6%
Residential care	4%
Sitting services	4%

“Very restricted.”

“Nowhere near enough services available.”

“The services we receive, though excellent and very much appreciated, are approximately 10 hours a week out of 168 hours in a week. Also, they are a set time every week.”

“I feel forgotten and ignored. Society does NOT understand our lives. Listening and understanding what we say our lives our like professional services and social care we are so unfunded with minimal resource.”

Barriers

We asked carers whether there were any barriers to them accessing support. 47% of responding carers said it was because they don't know what services are available to them.

Over a quarter of responding carers (28%) said the cost of care was too high, and 11% said the charges for services has risen a lot.

17% of responding carers said that care and support services not meeting their needs was a barrier to accessing support, and 10% said the quality of care was a barrier.

17% of responding carers said they had been told there were no care and support services available to them, 11% said they had been told by care companies that there is a shortage of care workers and they don't have any more capacity to provide care, and 7% said there was shortage of care workers meaning they could not find care to buy.

We also asked carers if there were any other barriers that were preventing them from accessing support. Some carers told us that the person(s) they cared for was unlikely

to engage in services or was very resistant in asking for additional help, with some not accepting that they needed help.

“The person I care for is very resistant to asking for any help.”

“My wife is in denial about her condition. She will not attend local day care, we have tried 3 times.”

Other barriers highlighted included long waiting lists for services and services not being at appropriate times for them.

Table: barriers to carers accessing services and support

Barrier	Percentage
I don't know about the services that are available	47%
The cost is too high	28%
The care and support services available do not meet our needs	17%
I have been told there are no care and support services available	17%
I am not eligible for Government provided services	16%
Other	14%
Charges for services have gone up a lot	11%
Care companies have said there is a shortage of care workers and they don't have any more capacity to provide care	11%
The quality of the care is not good enough	10%
I am worried about the person I am caring for catching Covid-19	10%
There are no barriers to me accessing support	8%
There is a shortage of care workers which means I cannot find care to buy	7%
There is no transport available to take the person I care for to services	7%

“I only get a little bit of help. If I need any more I need to try and find carers and pay £50-£60 per hour as he needs two. We can't afford that, we would be left with nothing but our house crumbling around us and no money to pay the bills. In addition, before my husband got the four hours on a Thursday I did try and find some carers to assist. In all the places I phoned on the list provided by social services they had no one to spare for a few hours a week. So yes, I do feel a little helpless.”

Future support

When asked about support in the future, 18% of carers said they were confident that day services would continue, and 15% said they were confident they would have the practical support they need in the next 12 months.

12% of responding carers said they were confident that respite services would continue.

Nearly two thirds of responding carers (63%) said they felt uncertain about what services and practical support they may be able to access in the next 12 months, and 60% said they were worried that services would be reduced. 48% of responding carers said they were worried they may lose access to voluntary services due to funding constraints, and 59% said they were worried they won't be able to afford services or practical support in the future.

We asked carers if they felt that they were supported to provide as they wish and in a way that takes into account their own employment, health and wellbeing, and education. Only 11% of responding carers answered yes. 53% of responding carers answered no. 20% of responding carers said that sometimes they felt they were supported to provide care as they wished and in a way that takes their

employment, health and wellbeing, and education into account, and 16% said they were not sure.

11% of responding carers said they felt that they had access to the right information and could make informed decisions. Over half of responding carers (51%) said they did not feel that they had access to the right information and could make informed decisions, 29% of responding carers said they did sometimes, and 9% were unsure.

Carers' needs

62% of responding carers said they did not feel their needs as a carer are recognised.

When asked if there was anything that would help them with their caring role, 61% of responding carers said better recognition from the Government of their needs would help. 55% of responding carers said more support to be able to look after their own health and wellbeing would help them.

52% of responding carers said that more support from health care professionals would help them, and 51% of responding carers said more information and advice about caring would be helpful.

Nearly half of responding carers (49%) said more breaks or time off from caring would help them and 48% said more support from social care professionals.

“Overall understanding would be helpful.”

Table: what would help carers

Measure	Percentage
Better recognition from the Government of my needs as a carer	61%
More support to be able to look after my own health and wellbeing	55%
More support from health care professionals	52%
More information and advice about caring	51%
More financial support	49%
More support from social care professionals	48%
More breaks or time off from my caring role	49%
Increased choice in which services I can access	46%
Better understanding and recognition of unpaid carers from the general public	46%
More support from the social security system (e.g. a rise in Carer's Allowance)	45%
More affordable care services for the person I care for	40%
Better quality care services for the person I care for	35%
Support to prevent/reduce my loneliness/social isolation	28%
Better support to return to or maintain paid work	26%
More learning and training opportunities about caring	24%
More support from family and friends	21%
More support so I can maintain/build my relationships with others	19%
A more supportive employer to help me stay in paid work	10%

Future challenges

One of the biggest challenges carers said they may face in the next 12 months was the changing needs of the person they are caring for, with nearly three quarters of responding carers (71%) identifying this as a challenge.

63% of responding carers said the rising cost of living and how that will impact on their financial situation would be a challenge for them, and 63% of responding carers also said that they were concerned about the impact of caring on their physical and/or mental health.

Over half of responding carers (51%) said being able to have regular breaks from caring would be a challenge for them in the next 12 months.

Other challenges identified by responding carers included transitioning from children to adult services and having to return to work or increase working hours in order to make ends meet.

71%



Nearly a quarter of responding carers said the changing needs of the person they care for could be a challenge for them in the next 12 months

63%



Over three fifths of responding carers said the rising cost of living would be a challenge for them in the next 12 months

Recognition

Many people who take on caring responsibilities do not recognise themselves as a carer straight away. This could be due to a number of reasons, including not being told they are a carer by health and social care professionals, or just seeing themselves as a family member or friend. Identification - both self-identification and identification by professionals - is key in carers getting the support they need.

Identification

Over half of responding carers (56%) said it took them over a year to recognise themselves as a carer with 38% stating it took them 3 years or longer.

27% of carers recognised their caring role immediately.

We asked carers what, if any, were the reasons they did not immediately recognise themselves as a carer. Two thirds of responding carers (66%) said the reason was that they saw themselves primarily as a family member or friend.

42% of responding carers said that taking on their caring role was a gradual process so it took them a while to realise they were a carer, and 32% said they didn't think the amount of support they were providing was

enough for them to be identified as a carer.

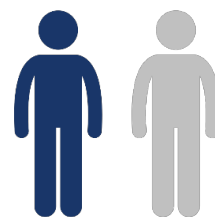
30% of responding carers said they were so busy caring that they didn't recognise the role they were undertaking, and 28% said that no one told them they were a carer. 24% of responding carers said they didn't feel like they deserved recognition for their role, 23% said they didn't know much about the support available to carers, and 19% said they didn't understand what was meant by the term 'carer'.

“Because I care for my husband and we have had a good and long marriage, I saw my role as a natural progression and part of the vows I took when we married.”

“As a mother, caring for your child is not at question.”

56%

Over half of responding carers took over a year to recognise themselves as a carer



Skills

Caring can be a varied role with carers having to learn new skills and adapt their way of life in order to provide care and support. Many of these skills are transferrable and can help carers in other areas of their lives.

Skills gained through caring

When asked if they felt they had gained any skills because of their caring role, resilience was the most common skill identified, with 61% of responding carers stating this is something they had gained.

Over half of responding carers (53%) said they had gained empathy through being a carer, 34% said they had gained advocacy skills and risk management skills, and a third (33%) said they had gained communication skills.

The table below shows the wide range of skills responding carers have gained through their caring role, which is something that should be recognised.

Table: skills gained through caring

Skill	Percentage
Resilience	61%
Empathy	53%
Advocacy	34%
Risk management	34%
Communication skills	33%
Time management	30%
Financial management	18%
None of the above	18%
Partnership working	11%
Other	4%

Discrimination

Unfortunately, responses from carers indicate that they face discrimination or unfair treatment as they navigate their role.

The Isle of Man Government's Equality Act 2017 was introduced to provide the right to equality of opportunity and protection from discrimination, harassment and victimisation in the Isle of Man.⁵

The changes stated in this law provide equality of opportunity and makes it unlawful to discriminate, harass or victimise a person when providing goods, services or public functions, in education, in employment or as a member of an association on the basis of a person's:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation⁶

The law also extends to cover cases where those who experience 'less favourable treatment' is because of the victim's association with someone with a protected characteristic.⁷ This definition aims to help improve protection for many people caring for those with a protected characteristic.

Unfair or unfavourable treatment

Carers were asked if they felt they had ever been treated unfairly or unfavourably as a result of their caring responsibilities in a list of various contexts.

⁵ Isle of Man Government, www.gov.im/news/2019/dec/30/new-equality-legislation-in-full-effect-from-1-january-2020

⁶ Isle of Man Government (2017), Equality Act 2017

⁷ Isle of Man Government (2017), Equality Act 2017

Over half of responding carers (55%) felt they had not been treated unfairly or unfavourably in any of the situations listed.

Nearly one fifth of responding carers (19%) said they felt they had been by the public, and 17% said they had been when receiving public services. 16% of responding carers said they felt they had been treated unfairly or unfavourably at work, and 14% felt they had when receiving public services.

Additionally, one in ten responding carers (10%) said they felt they had been when using financial services, for example a bank or building society, 7% said they felt they had when using businesses or shops, and 5% said they felt they had when renting a house or receiving housing services.

“No-one sees the carer. Everyone rises and gushes over a person with a visible disability... People almost shove you out of the way or ignore you completely in an attempt to look like a

caring helpful person to your disabled partner but are downright rude to the carer. Both in professional and public places.”

“Public services - I don't think doctors/education professionals understand how mentally, physically and emotionally exhausting this 24/7 situation is.”

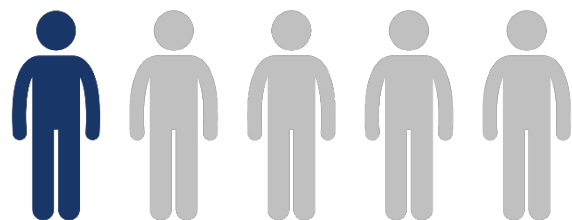
“At work people with children seem to be given benefits but it is not viewed in the same way if I have to care for an elderly parent.”

“That's more to do with the social stigma around benefits. I just kind of get slapped with the “scrounger” label for being on benefits and people don't understand that due to my caring duties....”

“Poor. Unimportant. Unseen. Unappreciated. I'm just a carer, not a person.”

19%

Nearly one fifth of responding carers said they felt they have been treated unfairly or unfavourably by the public



Next steps

In 2015, Carers UK and the University of Sheffield published 'Valuing Carers 2015: The rising value of carers' support' which reported that care provided by unpaid carers in the UK was estimated to be £132 billion per year. This equates to more than the total spending on the NHS in England.⁸

In the Isle of Man, the number of carers continues to rise. With our health and social care system under increasing pressure to meet the needs of our Island's residents, now and in the future, it is imperative that the carers within our community are adequately supported to ensure those who need care are able to remain independent in their own homes for longer.

In November 2022, the Department of Health and Social Care's 2022-2023 department plan, published a vision to provide 'Right Care, Right Time, Right Place'. Furthermore, one of the Department's three priorities places an emphasis on 'supporting care at home and in the community' with a view to ensuring communities have accessible services and support networks that enable people to remain at home for longer and avoiding reliance on hospital based services.

The results of the survey highlight the importance of a developing a strong working partnership between Government and the third sector in order to produce meaningful improvements and better outcomes for carers. This will mean that for carers, they will be provided with appropriate support to allow them to undertake their roles so they can balance their own needs whilst caring for others.

Crossroads and the Department of Health and Social Care are now actively working to develop a National Carer Strategy and Delivery Plan.

Over the coming months, this partnership will establish the key themes and actions required to address the challenges faced by those in a caring role with the intention of releasing the Carer Strategy and Delivery Plan in Summer 2023.

⁸ Lisa Buckner, University of Leeds & Sue Yeandle, University of Sheffield, Carers UK (2015), Valuing Carers 2015: The rising value of carer's support

