THE STATE OF CARING IN THE ISLE OF MAN

2024-2025

Crossroads
Putting carers first

Isle of Man Government
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Department of Health and Social Care
Rheynn Slaynt as Kiarail y Theay

State of Caring Survey

The ‘State of Caring’ survey has been carried out twice previously, in 2018 and 2022. The survey asks carers to share their feedback and experiences to help us understand the state of caring on Island.

In 2024, the survey was carried out 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 2024, 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 370 carers responded to the survey. Of the respondents:

- 1% are aged 18-24, 5% are aged 25-34, 9% are aged 35-44, 18% are aged 45-54, 34% are aged 55-64, 22% are aged 65-74, 10% are aged 75-84, and 1% are aged 85 and over.

- 82% are female, 16% are male, and less than 1% identify as non-binary.

- 93% are White (Manx, English, Welsh, Scottish, Northern Irish, or British), 2% are White (Irish), and 3% are White from a different background. 0.2% are Asian/Asian British (Chinese), 0.2% are Arab, and 0.7% are from an Asian background that was not listed. 0.2% are from a Black/African/Caribbean background that was not listed and 0.7% are from a different ethnic group that was not listed.

- 71% are married or in a domestic partnership, 13% are single, 6% are divorced, 4% co-habit, 4% are widowed, and 0.5% are separated. 1.5% of carers who responded had a different marital status or preferred not to say.

- 37% live in the East of the Island, 23% live in the North of the Island, 16% live in the South of the Island, 12% live in the West of the Island, and 12% live centrally.

- 22% have childcare responsibilities for a non-disabled child under 18 years old.

- 32% have a disability themselves.

- 37% are currently in employment. Of those, 23% are in full time employment and 14% are in part time employment. 39% are retired, 11% are unable to work, and 3% are unemployed. 2% are in full or part time education.

- 3% have been caring for one year or less, 14% for 1-2 years, 24% for 3-4 years, 22% for 5-9 years, 14% for 10-14 years, 5% for 15-19 years, and 18% for 20 years or more.

- 78% care for one person, 17% care for two people, and 5% care for three people or more.

- 45% are a parent to the person they care for, 38% are a spouse or partner, 13% are a child, 4% are a sibling, 3% are a neighbour or friend, 2% are a grandparent, and 2% are another family member such as an aunt or cousin.

- 38% care for 100 hours or more each week, 7% for 80-99 hours, 6% for 60-79 hours, 11% for 40-59 hours, 15.5% for 20-39 hours, 13.5% for 10-19 hours, and 9% for 0-9 hours.

- 86% provide practical help to the person(s) they care for, 81% help with arranging and/or coordinating care and support, medical appointments and other help, 80% provide emotional support, and 59% provide personal care.

- 75% live with the person(s) they care for.

- 30% cannot leave the person(s) they care for on their own, and 45% 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 370 carers.

Table: the type of care being provided by carers

Type of care	Percentage
Practical help (e.g., cooking, cleaning, housework)	86%
Arranging and/or coordinating care and support, medical appointments, and other help	81%
Emotional support	80%
Helping with financial matters and/or paperwork	73%
Helping with medication	71%
Personal care (e.g., bathing, washing, dressing, using the toilet)	59%
Help with moving around (e.g., walking, getting in and out of bed)	43%
Other	10%

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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.

Progress since the last survey

Using the feedback and results from the 2022 ‘State of Caring’ survey, Crossroads and the Department of Health and Social Care produced a Carers Strategy 2024-2034 which recognises the importance and contribution of carers in our society, and makes commitments to ensure they are better supported, valued and included.

The strategy is designed to address the challenges that were raised in our previous 'State of Caring' report, and aims to continue raising awareness of carers, their positive impact of the health and care system and how they support our strategic direction of providing more care at home and in the community.

The strategy sets out a framework with five key priorities to address the challenges facing carers and provides a detailed action plan on how this is to be achieved.

After consultation, the strategy was approved by Tynwald in June 2024.

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[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

The approval of the strategy was an important step in acknowledging the invaluable work carers in the Isle of Man do, and its associated action plan provides clear aims and objectives on how this can be achieved.

As part of the action plan, a carers steering group has been established, consisting of representatives from Crossroads, Alzheimer's Society, Department of Health and Social Care, Manx Care and Public Health, to coordinate the delivery of the strategy action plan. The steering group will utilise the statistical and trend data from the State of Caring report to develop appropriate actions that seek to address issues impacting carers the most.

Health and wellbeing

Being a carer can significantly impact a person's physical, emotional, and mental health. This may be due to a range of factors, including the physical demands of caring, the lack of meaningful breaks, and not being able to prioritise their own health needs.

Physical and mental health

15% of responding carers said their physical health was ‘bad’ or ‘very bad’. 44% described their physical health as ‘fair’, which was the most common answer.

18% said their mental health was ‘bad’ or ‘very bad’. 43% described their mental health as ‘fair’, which was the most common answer.

“Caring is draining, both physically and mentally. I am a resilient person, but there are days when I want to just sit down and cry.”

“Mentally it’s difficult. I feel like I’m drowning.”

Following on from this question, we asked carers which aspects of their health and wellbeing they worried about the most, with over three quarters (76%) saying they were worried about feeling tired.

74% of responding carers said they were worried about feeling stressed or anxious, and 58% were worried about not having the time to prioritise their physical and mental health.

56% of responding carers said they were worried about getting enough sleep and half (50%) said they were concerned about not being able to take a break.

36% of responding carers said they were worried about feeling lonely or isolated, and 335% said they were worried about feeling depressed.

“I feel lonely and isolated, and that I’m missing out on so much.”

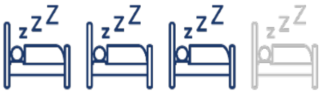
“Sometimes I feel quite hopeless with the day-to-day grind of caring. It is never ending.”

“I am constantly tired and feel isolated. I am worried all the time.”

When asked whether their health had changed since becoming a carer, 85% of responding carers said their health had suffered (compared to 82% in 2022). Of those, nearly half (48%) said their health had suffered slightly and 37% said their health had suffered significantly.

Only 14% of responding carers said their health had not changed, and 1% said their health had improved.

74%



Nearly 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 tired	76%
Feeling stressed or anxious	74%
Not having the time to prioritise my physical and mental health	58%
Getting enough sleep	56%
Being unable to take a break	50%
Impact on my relationships	44%
Getting enough exercise	38%
Feeling lonely or isolated	36%
General health deterioration	36%
Feeling depressed	35%
Getting health appointments when I need them	34%
Eating a balanced diet	29%
Feeling panicked	20%
Persistent physical injury caused by or exacerbated by caring, such as back strain	18%
Other	10%

Respite

Carers were asked if they had taken a break from their caring role in the last 12 months, with 39% of responding carers stating they had been able to take a break.

Just over three in five responding carers (61%) said they had not taken a break, and of those, 37% said they hadn't tried to take a break because they thought it was too difficult. 11% 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, 12% 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 (17% in 2022).

Comments in the survey also highlighted that many carers feel that even when they did get a break, it was difficult not to worry about the person they cared for.

61%

Over three in five responding carers said they have not taken a break in the last year

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, 45% of responding carers agreed they were involved in decisions about the discharge (an increase from the 2022 figure of 36%). However, 37% disagreed with this.

Only 15% of responding carers agreed they were asked about their ability and willingness to care, whereas 68% disagreed that they had been asked about this.

> ***"There is no compassion, understanding or care about carers. I feel like I don't exist. I am doing the job of care and yet I am invisible."***

Nearly three in five of responding carers (58%) 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 17% agreeing with this.

> ***"I have not been given all the information and support required to make decisions in the future."***

When asked to what extent they agreed that they were under no pressure to care and felt fully prepared and supported, 17% 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'.

39% of responding carers said their life was 'good', 'very good' or 'excellent', 45% said it was 'sometimes good or sometimes poor', and 16% said it was 'poor' or 'very poor'. These results are similar to those from the 2022 survey.

> ***"I have a good, positive, loving relationship with the person I care for, but there are so many things we can't do and I often have to put my life on hold or have to turn down invitations out of guilt."***

> ***"I feel exhausted all the time trying to juggle work and my caring role which means my quality of life has really diminished."***

Additionally, when asked if they felt safe as a carer, 66% of responding carers said they did (a decrease in the 2022 figure of 70%).

Table: how carers reported their quality of life

Aspect	Percentage
Excellent	3%
Very good	10%
Good	26%
Sometimes good but sometimes poor	45%
Poor	11%
Very poor	5%

Social impact of caring

Many carers often report feelings of loneliness and isolation due to their caring role, along with concerns about their future. Additionally, it can be difficult for carers to socialise with family members or friends due to the demands of caring.

Social life

We asked carers to describe how their social life has changed since taking on their caring role.

87% of responding carers said their social life had suffered, with 53% of those stating it had suffered significantly. 10% of responding carers said their social life had not changed, and 3% said it had improved.

Over three in five of responding carers (62%) said they felt or had felt they were missing out on aspects of their life. 29% 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.

Additionally, when asked if they wished or had ever wished they could escape from their situation, 44% of responding carers said yes, 37% said sometimes and 19% said no.

37% of carers said they did not feel they had a life outside of their caring role, and 43% said they only feel they do some of the time.

> ***"It can be so hard meeting up with friends or attending events."***

> ***"My social life is non-existent. I have no time for myself anymore."***

Carers were asked whether they expected that things would be different at this point in their life, with 72% of responding carers stating they did.

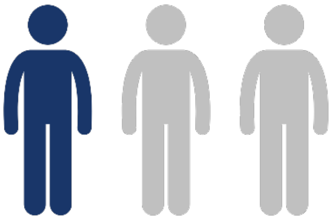
Loneliness and isolation

Carers were asked to tell us how often they felt lonely. 23% of responding carers said they felt lonely often or always and 46% said they felt lonely sometimes. 15% of responding carers said they hardly ever felt lonely and 13% said they never felt lonely.

Additionally, 79% 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.

37%

Over one third of responding carers said they did not feel they had a life outside of their caring role



"I feel like people don't understand how lonely and isolating our life can be."

When asked if there was anything that would help them to feel less lonely, 61% of responding carers said more understanding and recognition from society about the role of carers would help, and 58% 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 (41%), being able to take part in physical or leisure activities (34%) and support with paying for social activities (25%).

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.

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. 43% said they sometimes felt positive about their future.

Over a third of responding carers (37%) said they felt discouraged about their future, and 7% said they did not think things would work out for them in the future.

"I worry what will happen in the future. I try not to think about it because it's too hard."

Table: what might help carers feel less lonely

Aspect	Percentage
More understanding and recognition from society about the role of carers	61%
Being able to take a regular break from caring	58%
Access to emotional support services	41%
Being able to take part in physical or leisure activities	34%
Support with paying for social activities	25%
Feeling able to talk to my family and friends about my caring role	24%
Being in contact with other carers	23%
Being able to take part in education/training opportunities	21%
Other	7%

Financial impact of caring

Caring often comes with additional expenses, such as specialist equipment or transportation costs, which can place a significant financial burden on carers. As a result, some are now unable to afford basic essentials like food, heating, or other necessities.

Overview

Over three in five of responding carers (63%) said they had been financially affected because of their caring role.

70% of responding carers said they were worried about living costs and whether they could manage in the future, and 30% of carers said they were struggling to make ends meet. Nearly one in five carers (18%) said they were in or had been in debt at some point because of caring. 17% said they were struggling to afford the cost of food, and 14% said they cannot afford utility bills like electricity, gas, and water or telephone bills. 17% of carers said they could afford their bills without struggling financially.

"Our savings are rapidly disappearing due to the cost of care and respite."

"We keep our lights off most of the time and use blankets instead of putting the heating on as we can't afford it."

"I have to keep dipping into my savings to make ends meet."

"I am worried about the future and how we will afford to live when all of our money is spent on care."

How carers are coping

We asked carers who were struggling to make ends meet how they were coping. 70% of carers said they were cutting back on luxuries, and 57% said they were cutting back on hobbies or leisure activities.

Half of carers (50%) said they were cutting back on seeing friends and/or family members, and 48% said they were using their savings.

One quarter of responding carers (25%) said they were cutting back on essentials such as food and heating, and 13% of carers said they were not coping.

70%

70% of responding carers said they were worried about living costs and whether they could manage in the future

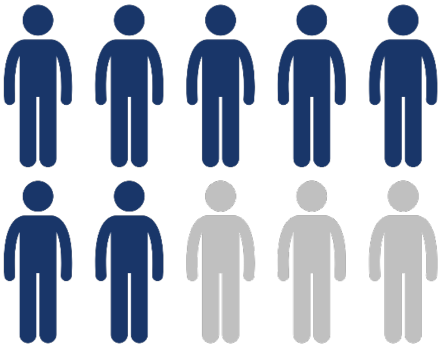


Table: how carers struggling to make ends meet said they were coping

Measure	Percentage
Cutting back on luxuries	70%
Cutting back on hobbies/leisure activities	57%
Cutting back on seeing friends/family	50%
Using savings	48%
Cutting back on essentials (like food and heating)	25%
Using my bank account overdraft	21%
Borrowing from family or friends	21%
Using credit cards	16%
Cutting back on support services which help with caring	14%
Falling into arrears with utility bills	13%
I am not coping	13%
Falling into arrears with housing costs i.e. rent or mortgage payments	9%
Other	9%
Using food banks	7%
Taking out a loan from the bank	6%
Using pay day loans	2%

"I am terrified by the extremely high costs of care. When my husband does get respite all of our income and savings are used to pay for the care."

Benefits

Only 29% of responding carers said they received Carer's Allowance (a decrease from the 2022 figure of 33%). 45% said they or the person(s) they cared for received Disability Living Allowance, and 22% of responding carers said they received Attendance Allowance. One quarter of responding carers (25%) said they received no financial support from the benefits system.

The standard rate of Carer's Allowance in the Isle of Man for 2024/2025 was £165.75 per week, which is an increase from the 2022/2023 rate of £140.35 per week. Positively, the Island's rate is still just over double the 2024/2025 standard rate in the UK of £81.60 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 £192 per week
- Not be in education of more than 21 hours per week

When carers were asked what would help them with their caring role, 43% of responding carers said more financial support would help, and 42% said more support from the social security system, for example a rise in Carer's Allowance, would help.

29%

Less than a third of responding carers receive Carer's Allowance

Employment

Many carers balance their caring responsibilities alongside paid employment, which can be extremely challenging. A significant number of carers report feeling tired, stressed, and overwhelmed as they struggle to juggle both work and their caring role.

Overview

Nearly three in five responding carers (58%) said their employment had been affected by their caring role.

"I had to give up my profession as there is no meaningful support for carers."

"I had to take early retirement."

"I can't work full time anymore as it's too much to care and work."

Employers

77% of responding carers said their employer knew they were a carer, an increase on the 2022 figure of 71%. Of those, 51% of responding carers said their employer allowed them to have flexible hours, 16% said they were not allowed flexible hours, and 10% said they choose not to have flexible hours.

10% of responding carers said their employer did not know they were a carer.

Balancing 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.

46% of responding carers either agreed (23%) or strongly agreed (23%) that working from home enabled them to balance work and care more effectively.

71% of responding carers either agreed (41%) or strongly agreed (30%) that work gave them a break from their caring role. 8% disagreed and 1% strongly disagreed.

57% of responding carers either agreed (36%) or strongly agreed (21%) that they felt anxious about caring whilst working.

Over two thirds of responding carers (69%) either agreed (41%) or strongly agreed (28%) that they felt tired at work because of their caring role.

60% of responding carers either agreed (31%) or strongly agreed (29%) that they had given up opportunities at work because of caring.

27% of responding carers said not being able to work from home would make them consider leaving their employment.

61% of responding carers said they agreed (33%) or strongly agreed (28%) that they were worried about continuing to juggle work and care.

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

What would help

When asked if there was anything that might help them to balance work and care, 60% of responding carers said that more affordable, accessible and reliable, alternative care for the person they cared for would help them, and 60% also said that links to good information and advice would help them.

Over half of responding carers (50%) said that the ability to take time off with paid Carer's Leave would help them, and 49% said that a change to the eligibility criteria for Carer's Allowance allowing them to work more hours or take on higher paid work would help them to balance work and care.

When asked if an understanding line manager or employer would help them to balance work and care, 41% of responding carers said they already had this at work. Additionally, 32% said that they had recognition from their employer of their caring role.

"Flexible working and working from home have been fundamental in allowing me to continue working whilst caring for my child."

"You have to find out for yourself what support is available. More information would be helpful for carers."

Carer’s assessments

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

A carer’s assessment is a tool where carers can discuss how their caring role is impacting them and can signpost them to appropriate support.

Take up

Carers were asked if they knew they were entitled to a carer’s assessment. 80% of responding carers said they did not know they were entitled to one. This is similar to the 2022 figure of 84%.

When asked whether they had received a carer’s assessment in the last 12 months, 94% of responding carers said they had not received a carer’s assessment. This is up 2% on the 2022 figure. Of those who said they had received one, 5% waited less than six months to receive it, and 1% waited more than six months to receive it.

Barriers

For those who had not received a carer’s assessment, over three quarters of responding carers (76%) said they did not know what a carer’s assessment was. This is similar to the 2022 figure of 74%. Additionally, 3% of responding carers said they were declined a carer’s assessment.

> ***“I didn’t know I was eligible or how to request one.”***

> ***“I have never been offered a carer’s assessment so I didn’t know could have one.”***

> ***“I don’t know anything about a carer’s assessment, yet I have been a carer for years.”***

80%

80% of carers did not know they were entitled to a carer’s assessment

Confusion with Carer’s Allowance

From comments recorded by carers, there remains some confusion between carer’s assessments and Carer’s Allowance:

“My mother has been on Island for less than four years so is not entitled to any benefits.”

“I wouldn’t fit the criteria.”

The confusion between carer’s assessments and Carer’s Allowance highlights a clear need for greater awareness. Many carers are unsure of what support they are entitled to, which can prevent them from accessing the appropriate support they need.

Support and services

Many carers require both practical and emotional support to continue providing care. However, carers have told us they are not receiving the support they need, and in some cases, they are unaware 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. Half of responding carers (50%) said they were not aware of what is available to them. 40% of responding carers said they were aware of some of the services that were available, and 10% 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, services provided by the Department of Health and Social Care, through education, from a wellbeing partnership, from their own research, other third sector organisations, other carers and word of mouth.

Carers were also asked which services they currently accessed. 40% of responding carers said they were currently accessing activities and support provided by a local charity.

33% of responding carers are currently accessing support from paid care workers, and 29% are accessing day services. 10% of responding carers are accessing Government funded care.

Some carers commented they weren't accessing any services at all.

Carers were also asked whether they felt the services they did have access to were meeting their needs.

61% of responding carers said they did not. Many carers felt that what was available was very limited and that services were at capacity. Others felt that there was not enough flexibility in service provision and that many offered a 'one size fits all' approach.

61%

Three fifths of responding carers felt that the services they have access to are not meeting their needs

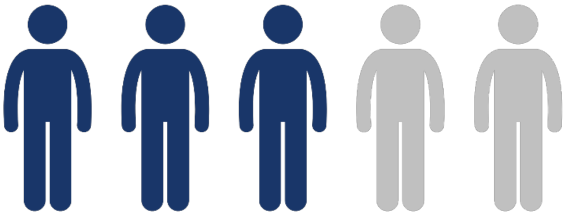


Table: services carers are currently accessing

Service	Percentage
Activities and support provided by a local charity	40%
Support from paid care workers	33%
Day services	29%
Activities provided by local carers' organisation	17%
Care homes for short respite breaks	17%
Government funded care	10%
Residential care	7%
After-school services for disabled children and young people	6%
Sitting services	6%
Other breaks services	2%

Barriers

We asked carers whether there were any barriers to them accessing support. 38% of responding carers said it was because they don’t know what services are available to them.

29% of responding carers said the cost of care was too high, and 7% said the charges for services has risen a lot.

19% said they had been told there were no care and support services available, and 16% said that the care and support services available did not meet their needs.

17% of responding carers said they were not eligible for Government provided services, and 11% said that care companies had said there is a shortage of care workers and they didn’t have any more capacity to provide care.

6% said there were no barriers to them accessing support.

Carers were also asked if there were any other barriers that were preventing them from accessing support.

Some carers told us that the person(s) they cared for were unlikely to engage with services or were very resistant to asking for additional help, with some not accepting that they needed help at all.

“My mother is very reluctant to go to day services or residential care.”

“My husband will not join in with any groups or engage with any support services.”

Other barriers highlighted included long waiting lists for services and limited transport provision.

Table: barriers to carers accessing services and support

Barrier	Percentage
I don’t know about the services that are available	38%
The cost is too high	29%
I have been told there are no care and support services available	19%
I am not eligible for Government provided services	17%
Other	17%
The care and support services available do not meet our needs	16%
Care companies have said there is a shortage of care workers and they don’t have any more capacity to provide care	11%
There is no transport available to take the person I care for to services	9%
There is a shortage of care workers which means I cannot find care to buy	8%
Charges for services have gone up a lot	7%
There are no barriers to me accessing support	6%
The quality of the care is not good enough	5%

“I would like to have more breaks but the cost is too high.”

“We are entitled to weekly respite however we only receive it every two weeks and they don’t have the staff or capacity.”

“We have been told we cannot access services as we are not eligible for support.

Future support

When asked about support in the future, over a quarter of responding carers (26%) said they were confident that day services would continue.

However, 29% of carers did not feel confident that day services would continue.

17% said they were confident they would have the practical support they need in the next 12 months, whereas 44% said they did not feel confident they would have the practical support they need in the next 12 months.

18% of responding carers said they were confident that respite services would continue.

69% of responding carers said they felt uncertain about what services and practical support they may be able to access in the next 12 months (an increase of 7% since the 2022 survey), and 63% said they were worried that services would be reduced.

Three in five responding carers (60%) said they were worried they won't be able to afford services or practical support in the future, and 56% said they were worried they may lose access to voluntary services due to funding constraints.

When asked 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, 10% of responding carers answered yes. 48% of responding carers answered no, 26% of responding carers answered sometimes, and 16% said they were not sure.

15% of responding carers said they felt they had access to the right information and could make informed decisions. 39% felt like they did not, 36% of felt they did sometimes, and 10% were not sure.

Carers' needs

Over half of responding carers (53%) said they did not feel their needs as a carer are recognised, and 51% said they did not have access to appropriate support that was suitable to them.

When asked if there was anything that would help them with their caring role, 57% of responding carers said better recognition from the Government of their needs would help. 51% of responding carers said more support to be able to look after their own health and wellbeing would help them.

46% of responding carers said that better understanding and recognition of unpaid carers from the general public would help them, and 46% said that more support from health care professionals would help them.

45% of responding carers said increased choice in which services they can access would be helpful, and 41% said more breaks or time off from their caring role.

> ***"If our daughter had better support from professionals and more choice of activities and support, I think we would help us to have a more balanced life."***

> ***"We need to be better at supporting each other and recognising the importance of carers."***

Table: what would help carers

Measure	Percentage
Better recognition from the Government of my needs as a carer	57%
More support to be able to look after my own health and wellbeing	51%
Better understanding and recognition of unpaid carers from the general public	46%
More support from health care professionals	46%
Increased choice in which services I can access	45%
More financial support	43%
More support from social care professionals	43%
More support from the social security system (e.g. a rise in Carer's Allowance)	42%
More breaks or time off from my caring role	41%
More affordable care services for the person I care for	40%
More information and advice about caring	39%
Better quality care services for the person I care for	29%
Support to prevent/reduce my loneliness/social isolation	26%
More support so I can maintain/build my relationships with others	21%
More learning and training opportunities about caring	19%
Better support to return to or maintain paid work	18%
More support from family and friends	18%
A more supportive employer to help me stay in paid work	8%

Future challenges

Carers were asked what, if any, were the main challenges they might face over the next 12 months.

Over three quarters of responding carers (76%) said that the changing needs of the person who is being cared for could be a challenge for them in the next 12 months.

68% of carers said that they were concerned about the impact of caring on their physical and/or mental health, and nearly half of responding carers (49%) said the rising cost of living and how that will impact on their financial situation would be a challenge for them.

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.

Recognition

Many people who take on caring responsibilities do not immediately recognise themselves as carers. This may be for various reasons, including not being identified as such by health and social care professionals, or simply viewing themselves as a family member or friend. Early identification - both self-identification and recognition by professionals - is crucial to ensuring carers receive the support they need.

Identification

Over half of responding carers (54%) said it took them over a year to recognise themselves as a carer, with 35% stating it took them five years or longer.

28% 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. 60% of responding carers said the reason was that they saw themselves primarily as a family member or friend.

49% 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 36% said they were so busy caring that they didn't recognise the role they were undertaking.

35% of responding carers said they didn't think the amount of support they were providing was enough for them to be identified as a carer, 29% said no-one advised them that they were a carer, and 20% said they didn't feel like they deserved recognition for their role.

18% of responding carers said they didn't understand what was meant by the term 'carer'.

"As the life partner it is difficult to find recognition as a carer. It is just expected of you or that you should do it for love."

"As a parent you don't consider yourself a carer."

"I'm not sure anyone has ever referred to me as a carer. It's my duty to look after my husband so naturally that's what I'm doing, but I appreciate that I am now the one who is responsible for his daily needs."

"I still don't really recognise myself as a carer."

Skills

Caring is a varied role that often requires individuals to learn new skills and adapt their way of life to provide effective care and support. Many of these skills are transferable and can benefit carers in other areas of their lives, including employment, education, and personal development.

Skills gained through caring

When asked if they felt they had gained any skills because of their caring role, 63% of responding carers said that resilience was something they had gained, and 55% said empathy was something they had gained.

A third of responding carers (33%) said they had gained communication skills through being a carer, and 31% said they had gained advocacy skills.

Table: skills gained through caring

Skill	Percentage
Resilience	63%
Empathy	55%
Communication skills	33%
Risk management	32%
Advocacy	31%
Time management	30%
Financial management	20%
None of the above	16%
Partnership working	15%
Other	10%

Other skills identified by carers included patience, compassion, collaboration with others and learning to accept people for who they are.

Discrimination

Unfortunately, responses from carers indicate that they often face discrimination or unfair treatment while navigating their caring role.

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

The Act provides 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 orientation[6]

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 Positively, over half of responding carers (53%) felt they had not been treated unfairly or unfavourably in any of the situations listed.

Nearly a quarter of responding carers (23%) said they felt they had been treated unfairly or unfavourably by the general public, and 18% felt they had been when receiving public services. responsibilities in a list of various contexts.

Additionally, 11% of responding carers said they felt they had been when using financial services, for example a bank or building society, and 9% said they felt they had been when using businesses or shops.

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[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

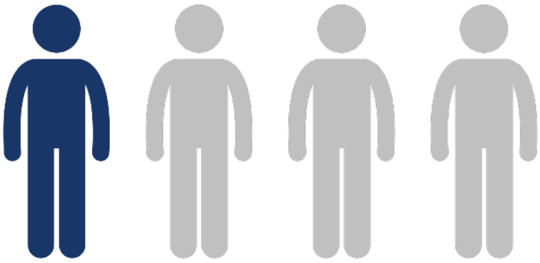
[7] Isle of Man Government (2017), Equality Act 2017

“People are not always tolerant of people with hidden disabilities. We get dirty looks and comments and people stare at us.”

“I have been treated unfairly when talking to medical professionals. They dismissed my needs as a carer.”

23%

Nearly a quarter of responding carers said they felt they had been treated unfairly or unfavourably by the public



Next steps

This report highlights the continued need for our Island's carers to be adequately supported to enable them to continue their caring role whilst balancing their own needs.

The findings outlined in this report continue to support the Carers Strategy Steering Group to deliver actions and initiatives that will address the issued being raised. The report continues to highlight the importance of listening to the voices of carers and we are committed to finding ways to make sure the views and experiences of carers, of all ages, are heard.

We look forward to continuing our partnership with the Department of Health and Social Care and building strong relationships with third sector and statutory partners for the betterment of carers in the Isle of Man to ensure they receive the appropriate support.

Signposting

If this report has raised any concerns or the need for support, the following organisations and statutory services can be contacted for further help and information.

Crossroads
Telephone: 01624 673103
Email: info@crossroadsiom.org

Adult Social Care

Southern Wellbeing Partnership
Telephone: 01624 686109
Email: SouthernWellbeingPartnership@gov.im

Western Wellbeing Partnership
Telephone: 01624 685846
Email: WesternWellbeingPartnership@gov.im

Northern Wellbeing Partnership
Telephone: 01624 686432
Email: NorthernWellbeingPartnership@gov.im

Eastern Wellbeing Partnership
Telephone: 01624 686207
Email: EasternWellbeingPartnership@gov.im

Alzheimer's Society
Telephone: 01624 613181
Email: isleofman@alzheimers.org.uk

Social Security Division
Telephone: 01624 685656
Email: socialsecurity@gov.im

Public Health
Telephone: 01624 642639
Email: publichealth@gov.im

Manx Care Advice and Liaison Service (MCALS)
Telephone: 01624 642642
Email: mcals@gov.im

Department of Education, Sport & Culture
Telephone: 01624 685808
Email: admin.desc@gov.im