



The State of Caring in the Isle of Man 2018-2019

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About the research

In June 2018 Crossroads Care published a Carer's Survey that was designed to gain knowledge about how carers in the Isle of Man felt about their caring journey, and to provide statistics that could be used to develop our services and our approach to supporting carers. We asked carers to share their experiences and thoughts on caring to help us understand how we could improve the lives of carers on island and ensure our services reflect the actual wants and needs of carers.

Method

The questions that formed the Carer's Survey were put together by members of Crossroads Care's senior management team (comprised of the Chief Executive Officer, Adult Services Officer, Children's Services Officer, and Business Support Services Manager), HR, and Fundraising Coordinator & PR. The questions were devised using past research findings and existing questionnaires including the Caregiver Burden Inventory, Psychological General Well-Being Index, World Health Organisation Quality of Life Assessment, Beck Depression Inventory, and Multidimensional Scale of Perceived Social Support.

Paper copies of the survey were sent to all carers on our current client database, and copies were also handed out at our Young Carers sessions. We also stated that any carers living in the Isle of Man could request a paper copy of the survey, regardless of whether they used a Crossroads service or not.

A covering letter was sent out with all paper copies explaining what the survey was for and why we were asking carers to complete it. The letter also included a stamped addressed envelope to enable carers to return the survey to us. The letter explained that the survey was anonymous and provided contact information in case of questions or concerns.

The survey also included a covering page which further detailed the reasoning for the survey and why it was of importance.

The survey was available online through Crossroads Care's website and social media platforms. Members of the senior management team also sent the survey to representatives from other local organisations including Autism Initiatives, Learning Disability Services, Mencap, MS Society, Adult Disability Services, Council of Voluntary Organisations, Adult Social Care, Education and Children and Families.

Response

232 surveys were sent to carers on Crossroads Care's current client database in paper form. 80 of these surveys were returned giving a response rate of 33.62%. 45 surveys were completed online; 6 through social media and 39 through the Crossroads Care website.

Overall 125 carers responded to the Carer's Survey between June and September 2018.

Of those who responded:

- 8% are aged between 11 and 18, 20% are aged between 19 and 39, 44% are aged between 40 and 59, 23% are aged between 60 and 79, and 5% are aged 80 or older.
- 82% are female and 17% are male. 1% are non-gender specific.
- 51% are in education or employment, either full or part time.
- 19% are single, 71% are married or in a domestic partnership, and 3% are co-habiting.
- 18% live in the north, 14% live in the south, 45% live in the east, 13% live in the west, and 10% live centrally.
- 20% care for more than one person.
- 50% are parent carers, 20% are child carers, 7% care for a sibling, 27% care for a spouse or partner, and 17% care for a non-relative.
- 95% live with the person(s) they care for.
- 82% deliver personal care.
- 53% cannot leave the person(s) they care for on their own, and 31% can only leave the person(s) they care for on their own some of the time.

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About carers

A carer is someone who provides unpaid care and support to a family member, friend, partner or neighbour whose health and well-being would suffer without their help. 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. A parent carer is a parent or guardian who provides care and support to their child due to disability, illness or complex care needs. Parent carers are likely to support their child for many months or years and can continue after some children have begun living independently. A young carer is a person under 18 who helps look after someone in their family, such as a parent or sibling, who has an illness, disability or mental health issue.

Carers may care for more than one person, and some themselves have a disability or illness. 3 in 5 people will become a carer at some point in their life, sometimes more than once. Anyone can become a carer, at any time, due to a sudden event such as an accident, or through a gradual process when a person's physical or mental health slowly deteriorates.

Carers can provide both practical and emotional support to the people they care for. Carers may help with the issues of daily living, domestic tasks such as cooking and cleaning, the finances of the person they provide care for, and physical tasks such as lifting and assisting with mobility. Carers are also responsible for ensuring those who they care for are safe and well looked after. This may mean that they have to undertake personal care tasks, the supervision and administration of medication and feeding tubes, and safety supervision. The type and amount of support provided may vary considerably from carer to carer depending upon individual needs. Therefore, it is not possible to fully define the role of a carer. Caring roles can vary over time and can be difficult to predict from day to day. Each situation is different, and the role of caring will not be the same for everyone.

Statistics from the Isle of Man Census Report 2011 indicate that there are 3,485 carers living in the Isle of Man.¹ Figures from the Isle of Man Social Attitudes Survey 2018 state that 18% of people in the Isle of Man provide unpaid care work.² In the 2016 Isle of Man Health and Lifestyle Survey, around 1 in 10 (9%) people said that they care for someone with long-term ill health or problems related to age. It was also stated that this figure was almost unchanged from a 2009 survey that indicated 8% of people in the Isle of Man were carers.³ 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



3 in 5

people will become
a carer at some
point in their life

¹ Isle of Man Government (2011), Isle of Man Census Report 2011

² Isle of Man Government Economic Affairs Cabinet Office (2018), Isle of Man Social Attitudes Survey 2018

³ Isle of Man Government (2016), Isle of Man Health and Lifestyle Survey 2016

another person.⁴ However, recorded figures from the Census and surveys do not uncover the true extent of caring in the Isle of Man. It is estimated that the true figure of carers on island is over 10,000.⁵ Additionally, figures from the Isle of Man Social Attitudes Survey show that the proportion of people providing unpaid care work on island is increasing.

Statistics on carers in the Isle of Man are not being regularly recorded. The key statistics on carers come from the 2001 Census which asked respondents multiple questions on caring. However, the 2011 Census only asked one question regarding caring, and the 2016 Census was designed in a short-form version meaning the questions asked in 2011 were not asked in 2016. Moreover, figures from the Isle of Man Youth Survey could not uncover the true number of young carers on island as the survey was only open to 11 to 18 year olds meaning that children under 11 were not able to participate and state if they were a young carer.

The Isle of Man Government's Carers Strategy 2007-2010 estimated that the true figure of carers in the Isle of Man is over 10,000 however this figure is now outdated. This number is likely to have increased, but there are no statistics available to uncover the true extent of caring on island. The only up to date figures on caring have come from Crossroads Care's Carer's Survey. In order to truly understand the current state of caring in the Isle of Man it is essential that more up to date and detailed statistics on carers are reported.

Moreover, since the Government's Carers Strategy there has been no further updated documentation to report on the progress and objectives that were promised. The Carers Strategy stated that the Isle of Man Government '**must recognise the need to continually review the Carers Strategy in order to ensure that it remains up to date, coherent, appropriate, focuses on issues affecting carers and responds to need identified**'.⁶ However, since this was published there has been no further strategies documented and there has been no updates on the key objectives that were set out in the strategy. Additionally, there has been no reported updates on the 2012 Isle of Man Carers' Charter or the Department of Health and Social Care's 2013 Carer Survey Report in which it was suggested that the survey would be repeated in the future.

Since the 2013 Carer Survey Report there has been no further surveys, reports or strategies on carers from the Isle of Man Government. The objectives and aims outlined in previous documents have not been reported on and therefore there is no way in which to measure their success. The Government's Carers Strategy was designed to support carers over '**the next ten years**'. With 2020 now less than one year away, many of the aims and objectives set out in the strategy have yet to be achieved. The document acknowledged that it would not be possible to implement all of the proposals simultaneously, but there are still big areas of the strategy that are unlikely to be implemented within the year meaning carers will not receive the support they were promised.

With an ageing population and a growing number of carers living in the Isle of Man, it is essential that they are given appropriate support to enable them to continue caring. The comments and statistics provided by the carers who responded to this survey demonstrate that we must act now to ensure the wellbeing of all carers and ensure they are given the help and support they need.

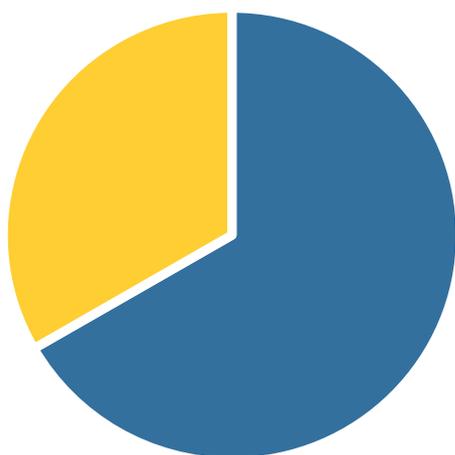
⁴ Isle of Man Government (2018), 2018 Isle of Man Youth Survey

⁵ Isle of Man Government (2010), Carers Strategy 2007-2010

⁶ Isle of Man Government (2010), Carers Strategy 2007-2010

The impact of caring on health

Caring can have an effect on a carer's physical, mental and emotional health; 66% of those who took part in the Carer's Survey said that their health had suffered because of their caring role. Of those who said that their health had suffered, 83% said that their health had suffered emotionally, 72% said that their health had suffered mentally, and 67% said that their health had suffered physically.



66%

of carers feel that their health has suffered because of their caring role

Statistics from the 2016 Isle of Man Lifestyle Survey indicate that around 1 in 6 carers provide over 50 hours of care each week.⁷ Providing this amount of care can be extremely demanding on carers and can significantly impact their health. 95% of carers who took part in the Carer's Survey live with the person(s) they care for which means that many are providing round the clock care. Research has shown that carers who provide round the clock care are more than twice as likely as non-carers to be in bad health.⁸

Additionally, 82% of carers deliver some form of personal care which can be physically demanding. 48% of carers said that they did not feel they were getting enough sleep, and 95% said they felt tired.

Carers may also find that their health can be impacted in numerous and various ways. 76% of carers who took part in the survey said that their health had suffered in more than one way. When asked to order the ways in which their health had suffered from the most to the least, 44% said they had been affected the most emotionally, 32% said they had been affected the most mentally, and 24% of those who answered said they had been affected the most physically.

When asked to expand on how they felt their health had suffered because of their caring role, comments included:

“Physical pain: constantly tired, get back and shoulder pain from lifting and carrying items my mother can't. Mentally and Emotionally: constantly mentally tired, have been recently diagnosed with anxiety and depression due to stressful life.”

⁷ Isle of Man Government (2016), Isle of Man Health and Lifestyle Survey 2016

⁸ Carers UK (2015), Facts About Carers 2015

“I had a nervous breakdown...”

“Drained (Emotionally) Drained (Physically) Drained (Mentally).”

“I am not the person I was, I struggle so much with my mental health... Physically I have sustained so many injuries my body is damaged and painful. Emotionally I struggle.”

“I am tired constantly.”

Common symptoms and effects mentioned in the survey included anxiety, depression and stress. 84% of carers said that they had or sometimes had feelings of worry or anxiety because of their caring role. These statistics correlate with UK statistics on carers. A report published by Carers UK found that 83% of carers were more stressed because of their caring role, 54% had suffered from depression, and 77% of carers felt more anxious.⁹

Comments from carers who took part in the survey also highlight the emotional and mental impact of caring with many saying that they felt worried due to their caring role and responsibilities:

“I worry that my health will suffer and that by the time I am in a position to do more for myself that I will be unable.”

“This is not for me, but my wife. My main concern is, at almost 83 that I could easily be the first to die. My concern is, that she could never survive on her own and I think that is my concern above all else.”

“I feel anxious about my future.”

Many carers also reported that they had developed a health condition due to the impact of caring. Carers can often find it difficult to find the time to attend their own medical appointments or treatment causing their own health to suffer. One participant of the Carer’s Survey said that it was **“difficult to concentrate on own ailments...”** because of their caring role. Another said: **“...it's difficult to find a sitter for even something as simple as a dentist appointment. As a carer your own needs, especially medically always take a back seat, because their needs are more pressing or urgent. You are constantly aware of their inadequacy to function without your help and at times this can feel quite suffocating.”**

The impact of caring on carers’ health is impacting their ability to provide long term, sustainable care. Many carers expressed that they felt they would be unable to provide care in the future because of the impact caring has had on their own health. When asked how long they thought they

84%

of carers have feelings of worry or anxiety because of their caring role

⁹ Carers UK (2018), State of Caring 2018

could continue to provide care for, several carers answered that they could only care as long as they were able to and as long as their health allowed. One participant stated: **“I can't [provide care] anymore. My health has suffered greatly and wife deteriorated beyond my capabilities.”** Other comments included:

“As long as I can stay fairly healthy and remain on my feet.”

“Whilst my health allows.”

“Whilst I am in good health it's fine. If I became ill, unwell, I would be unable to continue looking after my wife.”

“Until I physically can no longer manage the care needs.”

The Carer's Survey also asked carers to express how, in general, they currently felt. From this question many carers detailed how their health had suffered because of their caring role:

“Worn out.”

“Tired, stressed, anxious, worried.”

“Exhausted. Physically and mentally.”

“I am concerned about my own health and how long I am able to continue looking after my wife. These are, unfortunately, worries which continue to stay with me and remain close to the surface of my mind. I would think this is a very general issue for any carer who has serious health problems.”

“Constantly worried.”

“It's hard, it's emotionally and mentally draining.”

In addition to the worry that many carers experience, 20% of those who took part in the Carer's Survey said that they did not feel health professionals took them seriously or understood their situation.

Our island relies on unpaid carers to look after those who need care; their health and wellbeing is crucial in them being able to do so. In the Isle of Man Government's 2007-2010 Carers Strategy it was stated that carers save our island's economy between £40 and £90 million each year.¹⁰ This is the equivalent of Government spending on health each year. The cost of a nursing home on island can be up to £950 per week. The contribution carers make to our economy is undoubtedly of huge significance. Without good health they will be unable to continue providing care which will have a substantial impact on our island's economy.

¹⁰ Isle of Man Government (2010), Carers Strategy 2007-2010

The impact of caring on employment and education

A carer's employment and education are often negatively affected by caring. Being a carer can impact a person's ability to participate in paid work as many carers face having to work reduced hours or giving up employment completely in order to care. Additionally, many carers find that taking regular time off or working reduced hours can impact their long-term ability to work and can cause them to lack important skills and knowledge that are needed in certain areas of employment. This can make it very difficult for carers who are seeking employment after their caring role has ended.



51% of carers who took part in the Carer's Survey stated that they were currently in full or part time education or employment. Therefore, over half of our island's carers are juggling their caring role with work or education.



Over half of carers in the Isle of Man are juggling caring with work or education

It is also worth noting that over half (53%) of carers who took part in the survey said the person(s) they care for cannot be left on their own. Whilst some carers receive assistance and support for their caring responsibilities, for others caring is a full-time role meaning they are unable to participate in paid work or employment.

When asked if their employment or education had been affected by their caring role, 63% of those who answered said yes. When asked to expand on this and state in what way their employment or education had been affected, comments included:

"As the health of the people I care for has deteriorated I have no longer been able to juggle work with caring and had to give up my job."

"I gave up work because it is impossible to juggle the caring responsibilities that I somehow have fallen into."

"Annual leave [is] used for hospital appointments."

"I no longer can work, all my time is used to care."

"I have had to leave work with no notice and have been absent on many different occasions this year because of my son's admissions to hospital."

“Juggling a job with caring responsibilities and home responsibilities as well as managing school holidays feels like too much to think about.”

“From full to part time hours then stopped completely.”

“Reduced hours in order to accommodate the many medical appointments.”

Furthermore, 44% of carers who said their employment or education had been affected by their caring role said that they have had to give up work, and 23% of those who answered said that they now worked reduced hours. These statistics highlight the impact caring can have on a carer’s employment or education.

Reduced employment also causes financial hardship for carers, and many carers said that their financial situation had suffered because their caring role had impacted their ability to work. One carer said that due to their caring situation, their employment was affected with a **“change of hours which meant reduced pay”**.

When asked to explain how they felt in general about their caring role, many carers commented on the difficulties of caring and employment:

“Trying to hold full time employment and being a carer is very hard work.”

“It is difficult... Too much responsibility, running the home, being in charge of finances, holding down a job.”

“My partner can't work due to seizures and his memory problems... Because they always happen at night, up to two or three times, I often have to go to work exhausted and come home at lunchtime to check on him, change bedding or help him shower.”

“My employer knew I was a carer but didn’t allow me to change my hours. I have since changed to a new job but this does not pay as well. I feel like I am missing out because I am a carer.”

It is evident that many carers struggle with balancing employment with their caring responsibilities. Positively, 61% of carers said their employer or educator knew they were a carer and allowed flexible hours. However, 14% of carers stated that their employer or educator knew they were a carer but did not allow flexible hours. For many, work or education must fit around caring, not the other way around. Moreover, as a result of caring carers may miss job opportunities or promotions.

44%

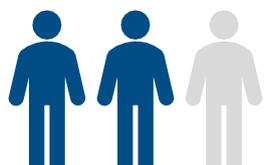
of carers have had to give up employment

Carers may then feel that they do not want to identify themselves as a carer to their employer as this may cause them to miss out on opportunities in work.

Many carers face a lack of understanding from employers, colleagues and teachers. Carers need awareness, flexibility, empathy and understanding within employment and education for them to be able to continue working or learning alongside caring. The Carer's Survey highlights that many of our island's carers are juggling work with care which, without the correct support, can be detrimental to both carers and those they care for.

The financial impact of caring

Caring can have significant financial implications for carers; approximately two thirds (67%) of those who took part in the Carer's Survey said that being a carer had affected them financially.



Two thirds

of carers have been
financially affected
because of caring

Due to reduced employment and other factors associated with caring, carers face a lower income compared to that of non-carers.¹¹ Carers often report that they struggle to make ends meet alongside the additional costs of caring. For example, carers may have to pay for care services, specialist equipment and transportation costs in addition to their everyday living costs. This, alongside the fact that many carers have to work reduced hours or not at all, means that carers can often struggle financially. In a survey carried out by Carers UK, a significant number of carers reported that as a result of their poor financial situation, they had to cut back on essentials

such as food and heating. It was also reported that many had used their own savings to finance care.¹²

Carers make a significant contribution to our island, especially our economy. As mentioned, carers save our economy between £40 to £90 million each year, and yet many carers are struggling with the cost of caring. Becoming a carer can be sudden and many are often unprepared for the impact caring can have on their lives, particularly financially.

Of the 63% of carers who said their employment or education had been affected by their caring role, many carers commented that this had a direct impact on them financially:

“[I was] made redundant from my job, reduced hours, reduced income which equates to reduced pension contributions so worry that when I reach retirement I won't have the standard of living expected.”

“Unpaid leave.”

“I now work reduced hours which means reduced pay. If I have to give up work we will have even less which worries me.”

Reduced hours or giving up employment can affect earnings, savings and pension entitlements. A carer's financial situation can be heavily affected by the impact caring has on their employment and

¹¹ Carers UK (2014), Caring & Family Finances Inquiry

¹² Carers UK (2018), State of Caring 2018

therefore it is essential that carers who participate in paid work are supported to ensure they do not suffer financially.

Other comments from the survey further highlight the financial implications caused by caring:

“We struggle as a family as we don't have family to help so if I become unwell it is very difficult to find someone to look after our children. We do not financially feel able to spend any quality time together as a couple as we cannot afford babysitters, especially as we would need someone used to dealing with a child with autism.”

“I am lonely, sad and broke.”

“Financially it is a struggle. We cannot do the things we used to enjoy because of money and we do not get any help. Our money goes on care and support so there is little left for us.”

In addition to the financial worries carers may face, many do not receive any financial support. The current rate for Carer's Allowance on island is £116.60 per week. This is comparatively high to the current UK rate which is only £64.60 per week.¹³

However, to qualify for Carer's Allowance in the Isle of Man carers must match the following qualifying criteria:

- 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.

Carers ‘must also have been living in the Isle of Man or the United Kingdom for at least 104 weeks (2 years) in the last 156 weeks (3 years) before the date on which you first satisfy all the other rules for Carer's Allowance.’¹⁴

The Isle of Man Government also state that a carer cannot receive Carer's Allowance if they get the same amount or more as other benefits or allowances including State Retirement Pension, a widow's benefit, Incapacity Benefit and Jobseeker's Allowance. Carers must also not be doing work for which they earn more than £112.00 per week.¹⁵

Whilst the rate of Carer's Allowance on island is almost double that of the UK, many carers still miss out because they do not meet the requirements or because they receive another form of allowance. Less than half (43%) of carers who took part in the Carer's Survey currently receive Carer's Allowance meaning that 57% of our island's carers are not currently receiving financial assistance for caring. This means that Carer's Allowance is not preventing financial hardship for our island's carers.

¹³ UK Government, Carer's Allowance, www.gov.uk/carers-allowance

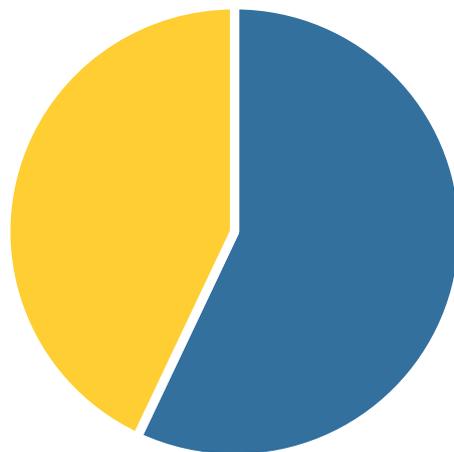
¹⁴ Isle of Man Government Social Security, Carer's Allowance, www.gov.im/media/7820/ca2-april-2016.pdf

¹⁵ Isle of Man Government Social Security, Carer's Allowance, www.gov.im/media/7820/ca2-april-2016.pdf

Carer's Allowance is designed to make caring easier for carers and yet it is clear that it is not benefitting those who need it. One carer who took part in the Carer's Survey commented:

“Because I work and own (mortgage) my home I am not entitled to any support except attendance allowance. If I need carers in or my husband needs to go somewhere overnight I have to pay private which I can't afford to. The government only look at what you earn and don't take any of your outgoings into account.”

Unfortunately, many of our island's carers are not receiving adequate financial support to help them on their caring journey and Carer's Allowance is not reaching those who need financial assistance.



57%

of carers do not
receive Carer's
Allowance

The social impact of caring

Socially, caring can have a negative impact on carers as their caring responsibilities can directly and indirectly cause their personal relationships and social lives to suffer.

95% of those who took part in the Carer's Survey said that they lived with the person(s) they care for meaning that almost all carers experience care as part of their everyday life and is something they deal with on a daily basis. Over half (53%) of carers said that the person(s) they care for could not be left on their own at all, and nearly one third (31%) said that the person(s) they care for could only be left on their own 'some of the time'.

85%
of carers said their
social life has
suffered

For many carers, caring can have a significant impact on their lives socially and on their personal relationships with family members and friends. Carers often report feelings of social isolation because of their caring role; 85% of carers said that their social life had suffered in some way, and 82% said they feel of have felt that they were missing out on aspects of their life.

Many carers also expressed how caring had affected their quality of life socially. Common feelings included isolation and loss of freedom:

"I have very little time to myself... I spend very little quality time with friends or my husband. I have never had any time off or away from my situation."

"I feel trapped and feel I have lost my freedom."

"I would like to meet more people. At the moment, my life is very restricted, confined to home. Apart from my 3 hours, I am unable to leave my wife unless I can obtain the services of someone to sit with her."

"I have lost my 40's, 50's and now my 60's."

"Virtually no personal freedom. I am with my husband 24/7."

"I no longer have a social life, and very few friends call at the house, this also includes my wife's friends."

"All of my time is spent looking after my daughter. I miss being able to see friends and do things outside of the house. I feel like I have lost my freedom."

When asked how, in general, they felt, many carers further detailed feeling of loneliness and isolation:

“I have cared for my husband for 6 years. We are unable to participate in social events or holidays... I often feel sad that I am not free to do all the things that I see my friends doing and although I do not resent my charges I sometimes resent the life that I have found myself leading.”

“I have lost touch with people and also the art of conversation, when I am in company.”

“I am 75 years old and look after my husband... I cannot leave him for long periods and arrange for someone to keep him company one night a month when I go out. Otherwise I am with him 24/7. This is very wearing mentally and whilst he appears "normal" our conversations are very narrow in subject and very repetitious. I am restricted from going out to meet friends for a coffee as I cannot leave him so everywhere I go, he comes with me. He also trails around the house after me and call if he cannot find me. I feel trapped and unable to do things I would like to be doing and feel the future is uncertain.”

“Lonely and trapped.”

“I just get frustrated when I can't go out with my friends. I feel I am being left out.”

“For me personally I feel that my role as a carer has meant that I've lost my own identity. My whole world revolves around my role as a carer and all that entails. As a result I don't really have any time to myself and no social life anymore. When family members are busy as they often are it's difficult to find a sitter for even something as simple as a dentist appointment.”

“Alone.”

56% of carers who took part in the survey rated their quality of life as either sometimes good but sometimes poor, poor, or very poor. 25% of carers said that they were discouraged about their future or did not think things would work out for them in the future. 68% of carers said that they wish or have wished that they could escape from their situation. Whilst the impact of caring on health, employment and finances is often discussed, the affect caring has socially is not always recognised yet it is evident from the comments and statistics collected from the Carer's Survey that socially, carers feel that caring is causing their lives to suffer.

The Carer's Survey also highlights that many carers feel alone and that they lack support. Many carers expressed feelings of loneliness as a result of their caring role and said that they miss being able to socialise and participate in activities. 35% of carers said they did not feel that their family understood their caring situation and 36% said they did not feel that they had someone to turn to for support when needed. Worryingly, a number of carers also expressed that they lacked the practical support to enable them to socialise due to current services:

“Respite care is difficult to plan in advance. Reayrt ny Baie being the only home willing to allow you to book a trip. Hospice refused to allow a respite for my husband, even though he has prostate cancer and most private homes only want to give respite if they have a room unused for full time care.”

“There is a lack of pre arranged respite facilities. Difficult to access flexible care, i.e. cover if you get an invitation to go out. I've had a regular evening/ afternoon off with carers coming in from an agency, but found trying to get any flexibility difficult with people not arriving when expected and vice versa.”

“Although this year I have been given one week in ten at Ramsey Cottage Hospital, they have indicated that this will not be available next year as they perceive him (my husband) to be "too well" for their type of care and have suggested I try residential care for him so that I can take a break... I do not know after October (my last period of respite) when I will next get a break and feel I should be enjoying life, taking holidays, visiting friends across which is not possible at the present time because of the lack of respite care available.”

Without practical support carers are unable to have time away from their caring responsibilities and can easily become socially isolated. Loneliness and isolation can be linked with mental health and, as mentioned, 72% of carers felt that their health had suffered mentally. Without regular breaks from caring, a carer's mental health can suffer demonstrating how the impact caring can have socially can lead to further negative outcomes for carers.

Personal relationships can also suffer as a result of caring; 73% of carers said that they felt their relationships with others had been affected by their caring role. Without support many carers are unable to take time off from their caring responsibilities which can result in them losing touch with family members and friends. There is also a lack of understanding surrounding carers and caring which can affect a carer's personal relationships and their ability to socialise as many carers do not feel understood or supported. Our island's carers need social support to improve their caring experience and to enable them to lead positive and fulfilling lives.

Services and Carer's Assessments

Appropriate services and support are essential in ensuring the wellbeing of carers. Without adequate support the lives of carers can suffer greatly.

Carers who took part in the Carer's Survey were asked if they were aware of what services and support were available to them as a carer in the Isle of Man; 21% answered yes, 21% answered no and 58% said that they were only aware of some of the services that were available to them on island.

Over half of carers (52%) said they did not feel that the services they had access to were meeting their care needs in regard to flexibility, availability and other needs. When asked to expand on this, comments included:



“There is not enough respite for carers especially in my situation which is 24/7 because my mother lives with me. I do not have any weekly/monthly respite.”



“Other than Crossroads, I do not have access to other services, other than Live At Home. They seem to be very busy, so I only request help if it is a last resort.”

Over half of carers do not feel that current services are meeting their needs

“Some of the services are not flexible due to there's not enough places.”

“Services are available to my daughter - nothing provided for me as a carer and no one to talk to about it.”

“Services are limited and there is often a waiting list. They are not really suitable for my situation. The services we have now are fine but not enough hours or very flexible.”

“No facility for respite care available for carer who wants to go away unless nursing care required via Ramsey Cottage. No designated respite beds in residential homes, only available at short notice.”

“Not enough staff to cover all visits. Lack of communication between various departments/agencies and family.”

“There is a significant shortage of services for parents with children, especially working parents who need assistance throughout all the school holidays or even respite. As a working parent I feel I am less entitled to services and support, there is a presumption that carers don't work, but some have no choice, especially single parents.”

“Not enough of them.”

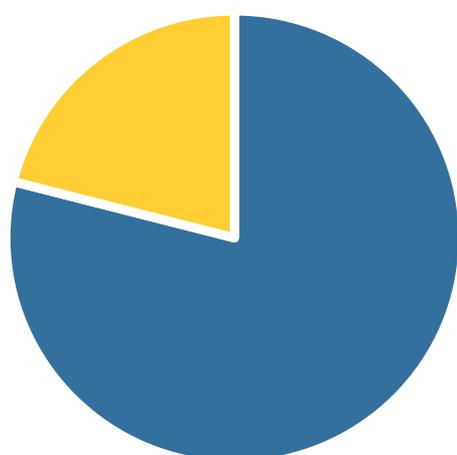
“We have requested overnight stays at Ramsey Resource and my son did not meet the 'criteria'.”

“It appears people are just box ticking, with phone calls instead of visits as they are too busy or passing the buck, not their remit or I need to ask someone else fill in a form or some other excuse.”

“It seems to all be about my wife's needs (she is who I care for).”

It is apparent from these statistics and comments that there is a lack of information being given to carers regarding what support and services are available to them, and a lack of flexibility within the services currently on offer.

Statistics show that there is also a lack of awareness surrounding Carer's Assessments. A Carer's Assessment gives carers the opportunity to access information, support and help. It also gives carers the chance to express how they currently feel about their role as a carer and the impact caring has on their life. Over three quarters (79%) of carers said that they were not aware of Carer's Assessments. Of the 21% of those who said that they were aware, 74% said that they had not received a Carer's Assessment. This means that only 5.5% of carers have received a Carer's Assessment. In comparison to UK statistics this figure is shockingly low; 66% of those who took part in Carers UK's annual State of Caring survey in 2018 said that they had received a Carer's Assessment in the last 12 months.¹⁶



79%
of carers are
unaware of Carer's
Assessments

¹⁶ Carers UK (2018), State of Caring 2018

Confusion and a lack of awareness surrounding Carer's Assessments means that many carers on island are not aware of what services and support are available to them. The Carer's Assessment gives carers the opportunity to review what help they need to support them in their caring role. It also provides carers with the opportunity to discuss with a professional how caring is affecting them and gives them access to information and services that can help them. It is therefore essential that all carers are aware of the Carer's Assessment as it can significantly improve their ability to provide care.

Additionally, in the UK young carers are entitled to a Young Carer's Assessment under the Children and Families Act 2014 and the Care Act 2014. The Care Act also places a duty on local authorities to provide a Transition Assessment to young carers before they turn 18.¹⁷ Whilst the rights of young carers are acknowledged in UK law, there is no similar legislation for young carers in the Isle of Man.

Furthermore, according to the 2018 Isle of Man Social Attitudes Survey, **'the great majority of carers indicate that they do not receive any form of external support for care work. However, SA18 finds that the proportion of carers in receipt of support has risen by 8%, from 10% in 2017 to 18% in 2018. Supported carers more frequently receive government support (12% in 2018), and the share of direct government support for carers is increasing at a relatively higher rate than support from charitable organizations.'**¹⁸ Whilst this positively shows the increase in the Isle of Man Government's support for carers, over 80% of carers who took part in the Social Attitudes Survey stated that they did not receive any support for caring.

Without appropriate information carers remain unaware of what services and support they have access to. Our island's carers need to be supported in order for them to continue providing care; statistics show that currently a high proportion of carers are unaware of what support they are entitled to and how they can access help.

¹⁷ UK Government, Care Act 2014, www.legislation.gov.uk/ukpga/2014/23/contents/enacted

¹⁸ Isle of Man Government Economic Affairs Cabinet Office (2018), Isle of Man Social Attitudes Survey 2018

Summary

The care provided by the increasing number of carers in the Isle of Man should not be taken for granted, and our island must support them. We must acknowledge the significance of their role in our society and make sure that their contribution is recognised.

It is clear that there is a lack of information detailing the true extent of caring in the Isle of Man as statistics on carers are not being recorded. Currently, key statistics come from the 2001 Census meaning that information about carers is outdated. It was estimated in the Isle of Man Government's 2007-2010 Carers Strategy that there was in excess of 10,000 carers living in the Isle of Man but without key statistics we are unable to uncover the true extent of caring on island.

Moreover, since the Government's 2007-2010 Carers Strategy there has been no further documentation to report on the progress and objectives that were promised. Whilst it was stated that the Government needed to continually review the strategy, there has been no further strategies published and no updates on the key objectives set out in the report. Furthermore, since the 2013 Carer Survey Report there has been no Government documentation on carers. Considering the increasing number of carers on island, it is worrying that their needs are not being addressed. The lack of information surrounding carers means it is not possible to know the true affect caring is having on our island's population and therefore it is difficult to establish a clear strategy on how to provide them with the support they need.

It is clear from the Carer's Survey that caring is having a significant impact on the health of carers in the Isle of Man. Statistics show that caring is affecting the physical, mental and emotional health of our island's carers. A high proportion of carers stated that their health had suffered because of their caring role and many reported that they had developed a health condition due to caring. Depression, anxiety, stress and tiredness were some of the most common symptoms mentioned in the survey which shows that caring has a notable effect on a carer's mental health. As a society we are becoming increasingly more aware of the importance of mental health, and statistics show that we need to recognise that for many carers, this is something that affects them. Many carers also expressed worry over their long-term ability to provide care. As several carers commented, poor health may stop them from caring in the future. One of the strategic goals in the Department of Health and Social Care's 'Health and social care in the Isle of Man – the next five years' strategy is **'to help people stay well in their own homes and communities, avoiding hospital or residential care whenever possible'**.¹⁹ To achieve this goal there will need to be more reliance on carers who will be responsible for keeping those who need care in their own homes. Without carers this goal will not be possible. With an ageing population, carers are having to provide more long-term care; from statistics and comments collected from the Carer's Survey and previous reports on caring, it is clear that the poor health of carers is affecting their ability to provide sustainable care. Our island relies on carers to look after those who need care, and good health and wellbeing is essential in them being able to do so.

¹⁹ Isle of Man Government Department of Health and Social Care (2015), Health and social care in the Isle of Man - the next five years

Caring can also have a major impact on a carer's employment and education. Over half of those who took part in the Carer's Survey stated that they were currently in some form of employment or education showing that there is a high number of carers who are juggling their caring role with other responsibilities. Nearly two thirds of carers stated that their employment or education had been affected in some way by their caring role, and many commented that in order to continue caring they had to give up work or reduce their hours. It is clear that caring can impact a person's ability to participate in paid work and that more needs to be done to support those who are juggling caring with paid employment. Statistics and comments from the survey also show that reduced employment can have a knock-on effect on a carer's financial situation. Reduced employment often leads to reduced pay which can ultimately cause financial hardship for carers. Positively, statistics from the survey show that many employers are allowing flexibility within employment to enable carers to remain in paid work. However, there is still a clear lack of understanding from employers, colleagues and educators surrounding carers and caring which can be detrimental to a carer's ability to participate in employment or education. There needs to be more flexibility and understanding within work and education to support carers and to prevent them from having to leave paid employment or educational opportunities.

Data collected from the Carer's Survey also highlights how caring has financial implications for carers; over two thirds of participants stated that being a carer had affected them financially. Many carers face additional costs relating to caring, such as having to purchase specialist equipment or pay for care services, which can cause them financial hardship. Moreover, as previously mentioned, a high number of carers have to give up work or work reduced hours in order to provide care which can lead to reduced pay and affect their savings and pension entitlements. Coupled with additional costs, this means that carers are more likely to be worse off financially than non-carers. It was recognised in the Isle of Man Government's Carers Strategy 2007-2010 that carers save our economy between £40 and £90 million each year. The money carers save our community and economy is hugely significant yet it is clear that many carers are facing high financial costs because of their caring role. Whilst Carer's Allowance in the Isle of Man is comparatively high compared to the UK, less than half of our island's carers are currently receiving it. Carer's Allowance is designed to support carers financially, yet statistics from the survey show that in reality, it is insignificant in preventing financial hardship. Carers need more financial support and assistance to ensure they can continue providing care long-term.

Caring is also having an impact on carers socially. A high proportion of carers stated that they felt their social life had suffered in some way due to their caring role and that they were missing out on aspects of life. Over two thirds of carers wished they could escape from their caring situation and many reported feelings of social isolation and loneliness. Loneliness is a common theme amongst carers, and many reported that they felt alone and that they lacked support. 72% of carers stated that their mental health had suffered because of their caring role, and this can be linked to feelings of isolation and loneliness. Worryingly over a third of carers stated that they felt they did not have someone to turn to for support or that their family understood their caring situation. It is clear from the comments and statistics collected from the survey that carers are lacking social support. The Carer's Survey also shows that current services are not providing enough practical support to enable carers to socialise and have a break from caring. A lack of availability and flexibility means carers are unable to have time away from their caring responsibilities which can often lead to further social isolation. The survey also highlights how personal relationships can suffer as a direct result of caring.

Without being able to have a break, carers can easily lose touch with family and friends which affects both their personal relationships but also their wellbeing and mental health. Whilst the effects of caring on a carer's health, employment and finances are often easy to recognise, it is more difficult to measure the social implications of caring, yet the Carer's Survey clearly shows how caring can directly and indirectly impact a carer socially.

It is also apparent from the Carer's Survey that many carers feel they are not receiving enough support to help them with their caring role. Statistics from the survey show that a high percentage of carers are not fully aware of what services are available to them, and over half feel that current services are not meeting their care needs. Common complaints mentioned included a lack of pre-arranged respite facilities and flexibility and availability within current services. It is also clear that there is a lack of appropriate information being given to carers about what support is available to them, specifically surrounding Carer's Assessments. Worryingly, over three quarters of carers are not aware of Carer's Assessments. There is a confusion and a lack of awareness surrounding the Carer's Assessment meaning that many carers are not being informed of what support and services they have access to. The Isle of Man Government's Carers Strategy 2007-2010 states that **'carers have the right to a statutory assessment and to be informed of that right and to have identified support needs implemented'**.²⁰ Additionally, the 2011 Social Services Act states that **'the carer has a right to a carer's assessment even if the person cared for has refused an assessment or the provision of social care services'**.²¹ Statistics from the Carer's Survey show that a high majority of carers are not being informed of their legal right to a Carer's Assessment and are therefore missing out on important information that could improve their ability to care. It is evident that more needs to be done to inform carers of what support they are entitled to.

Our island's carers allow thousands of people to remain in their homes and avoid residential and nursing care. This not only improves the quality of life of the people being cared for, it saves our economy millions of pounds each year. Yet it is clear that our carers are not being supported in a way that will enable them to continue caring in the future. Caring has a significant effect on carers in regard to health, employment and education, and impacts them financially and socially. The Carer's Survey highlights that many carers feel their lives are suffering because of their caring role and therefore it is essential that they receive appropriate support and information in order to improve their lives and enable them to continue caring in the future. Crossroads Care will continue to support carers and provide services that give them the recognition they deserve.

²⁰ Isle of Man Government (2010), Carers Strategy 2007-2010

²¹ Isle of Man Government (2011), Social Services Act 2011

Recommendations

Carers are the invisible army that save the Isle of Man economy millions of pounds each year. The support they provide cannot be taken for granted. Currently, their rights are not being recognised and they deserve to be acknowledged and appreciated for all they do. Every person has the right to feel safe but, as reported in the Carer's Survey, carers do not feel that their needs are being considered and looked after. Therefore, action needs to be taken to improve their lives and ensure they are able to continue providing care in the future.

Carer's Assessments

- Carers need to be informed of their right to receive a Carer's Assessment. This needs to be carried out by a wider range of organisations and not just at entry level to services.
- Carer's Assessments need to be revisited and repeated at least every 12 months to ensure carers are given appropriate support.
- Carer's Assessments should be carried out by trained staff from Crossroads Care. Crossroads is the only service provider in the Isle of Man that focuses on the carer, and therefore has the expertise and skills to carry out Carer's Assessments. Crossroads also has the capacity to increase the number of carers receiving a Carer's Assessment. The increase in numbers will lead to carers receiving better levels of support.
- The legal right of carers to receive a Carer's Assessment outlined in the 2011 Social Services Act needs to be implemented more effectively. Carer's Assessments need to be offered to all carers regardless of their situation as they are legally entitled to be protected by the Isle of Man Government.
- UK Carer's Assessments and the procedures surrounding them should be reviewed and considered regularly to ensure the Isle of Man's approach to Carer's Assessments is kept up to date with best practice.
- There should be a separate Young Carer's Assessment which should be carried out at least every 12 months. A Transition Assessment should also be introduced to support young carers going from children's services to adult services. This will ensure that young carers are not lost between the services and will give them the correct tools and information for the transition.
- The Carer's Assessment is there not only to support carers, but also to give the Department of Health and Social Care understanding of what services are needed to support carers. Therefore, the Carer's Assessment should include questions that provide information about the following areas:
 - What the carer's caring role is and how they feel about it.
 - How caring affects the carer's life and future goals.
 - How caring affects the carer's health and wellbeing, education and employment, financial situation, and personal relationships and social life.

The Carer's Assessment should also include clear information that informs carers of where they can receive help.

Information

- Carers should be given appropriate information that signposts where they can access support and services. Further work needs to be done on the information and resources available to carers to ensure that they have access to up to date documents and strategies that outline key information relevant to them. Additionally, carers should be given the appropriate tools to manage their caring situation.
- Carers need to be identified by anyone in contact with them, not just those within Social Care. Any organisation that is commissioned by the Isle of Man Government should be able to recognise when their clients are carers and should be responsible for onward referral or reference. Primary care service providers, including GP's, social workers and communities, need to recognise carers and support them to sustain their caring roles.
- The Isle of Man Government's Carers Strategy 2007-2010 needs to be reviewed. Since this strategy was published there has been no further documentation to report on the aims and objectives set out. There needs to be an updated report that measures the success of these aims and reports on the current state of caring in the Isle of Man.
- There needs to be more statistics collected relating specifically to carers that provide up to date and relevant information about caring. More questions on caring should be included the Isle of Man Census to ensure data around carers is kept up to date. There should be an additional survey or report that details statistics and information on young carers.
- The amount of support carers provide needs to be measured. This will allow the Isle of Man Government to understand how much should be spent on caring within the Department of Health and Social Care. Furthermore, sufficient pump priming should take place to allow Crossroads Care to increase carer support hours and reach more carers.
- Young carers should be recognised in their own right in the same way adult carers are. In the UK, young carers are specifically acknowledged in government legislation in the Children and Families Act 2014 and the Care Act 2014. Young carers in the Isle of Man should have more acknowledgment and tailored support.
- The Department of Health and Social Care's 'Health and social care in the Isle of Man - the next five years' plan encourages care in the home: **'providing care closer to people's homes and doing things right first time will improve the quality of our service at the same time as increasing efficiency and reducing cost.'**²² For the strategy to be a success this statement must be implemented and the quality of service given to carers needs to be improved to ensure they can keep their loved ones at home.

Health and wellbeing

- Carers need to be given more support to maintain and improve their health. Currently Crossroads Care is providing an additional 1,300 supportive hours per year to support carers' physical, mental and emotional health when they feel they are at crisis point. This should be a standalone, viable service that is offered to all carers to ensure their health and wellbeing is supported.

²² Isle of Man Government Department of Health and Social Care (2015), Health and social care in the Isle of Man - the next five years

- GP's should recognise and prioritise the health and wellbeing of carers. Carers should be able to turn to their GP for help and support in their own right and have their own health acknowledged.
- The current process of hospital discharge needs to be reviewed to ensure carers are recognised. Carer's Assessments should be included as part of the discharge process to ensure all carers are signposted to supportive services.
- There needs to be recognition of carer loss to ensure carers are given appropriate support, especially in regard to their mental health. Many carers struggle with grieving the life they knew or the life they thought they were going to have once they become a carer; they need to be supported to prevent mental and emotional health issues.

Employment and education

- There needs to be more understanding from employers to ensure carers are able to juggle work and caring. Employers need to offer flexible working arrangements to allow carers to continue working.
- Support and training should be given to carers who are looking to return to work, especially when their caring roles have finished.
- Young carers should be recognised within education and should be given appropriate support. Educators should be responsible for ensuring caring does not significantly impact their education and future opportunities.

Respite services

- More respite services are needed to provide further support to carers who need a break. Currently there are not enough services on island to meet the needs of carers. The number of carers on island is increasing and therefore there needs to be additional services to meet the resulting growing demand.
- Within respite services there needs to be more flexibility and availability to allow carers to book respite in advance, at short notice or in a crisis. Current services are not adequately meeting the needs of carers and are not enabling them to have a sufficient break from their caring responsibilities.

Documentation

- A new project or strategy needs to be implemented and published by the Isle of Man Government which considers the recommendations set out in this document and previous documents such as the Government's 2007-2010 Carers Strategy. There also needs to be reports on the progress of these documents to measure their success, and a strategy in which ongoing progress is considered and reviewed.
- The Isle of Man Government needs to regularly carry out research on carers and publish appropriate documents that relate directly to carers and that provide up to date information.

- The Isle of Man Census should include more questions on caring to provide relevant and up to date statistics. Questions on caring should be included in every census to ensure data is kept up to date.

All of the recommendations set out in this report are realistic and achievable. Together we can begin to improve the lives of carers in the Isle of Man.

Signed:

Jackie Betteridge, Chief Executive Officer of Crossroads Care



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