

# Carers' Rights in 2023

# Survey of carers in Scotland



November 2023

from recognition to rights

# Contents

Introduction	3
Who responded to the survey?	4
Awareness of Carers (Scotland) Act	6
Carers' rights in Scotland	7
The right to receive information and advice	8
The right to request an Adult Carer Support Plan or Young Carer Statement	10
The right to access support if you meet the local eligibility criteria	13
The right to be involved in the care assessment of the person you are caring for	15
The right to be involved in the hospital discharge planning of the person you are caring for	16
The right to be involved in the planning of local carer services	18
Making rights a reality for carers	19
Recommendations	21



## Introduction

The Carers (Scotland) Act came into effect 5 years ago on 1st April 2018. The aim of this legislation was to extend the rights of carers<sup>1</sup> in Scotland, and to ensure that carers were able to access the support that they needed to have a life alongside their caring role.

"It is the intention of the Scottish Government that Scotland's estimated 788,000 carers including 44,000 young carers are better supported on a more consistent basis so that they can continue to care, if they so wish, in good health and wellbeing, allowing them to have a life alongside caring.

TO VALATY YANNA

The Act makes real this ambition by furthering the rights of both adult and young carers."

- Carers (Scotland) Act 2016 Statutory Guidance

In March 2023, we carried out a survey with carers in Scotland to find out if they were aware of the rights that they had under the Carers (Scotland) Act. The survey also asked carers whether the legislation had made any difference to the support and services they have received over the past five years.

We had previously carried out surveys asking carers about their awareness of Carers Rights in 2018<sup>2</sup> and 2019.<sup>3</sup> By repeating the survey again this year, we wanted to gauge whether awareness of carers rights had increased since the Carers (Scotland) Act first came into effect.

This year we also included an additional question asking carers about their experiences of accessing support over the last 5 years and whether there had been any noticeable changes in local carer support during that period. The analysis of that question will be published separately.



A link to the survey was shared with local Carers Centres in Scotland as well as shared through social media channels. The survey was live between 20th March – 25th April 2023 and received responses from 1,278 carers from across Scotland.

This report provides a summary of the responses and an analysis of the comments from carers about their experiences of trying to access the rights that are enshrined in the Carers (Scotland) Act. Not all carers completed every question in the survey, so we have included the sample size for each of the questions.

We acknowledge that although we tried to reach a diverse range of carers from across Scotland, the carers who did respond to the survey would have been those who were able to readily access the online survey or had received support from their local carers centre to complete an online or paper version of the survey.

<sup>1</sup> In this report we use the term 'carer' to refer to anyone who is providing unpaid care to a relative or friend that requires care and support due to a disability or long term condition.

<sup>2</sup> https://www.carersnet.org/wp-content/uploads/2023/11/Carers-Rights-Survey-2018.pdf

<sup>3</sup> https://www.carersnet.org/wp-content/uploads/2023/11/Carers-Rights-Survey-2019.pdf

# Who responded to the survey?

# 1,278 carers from across all 32 local authorities in Scotland responded to the survey.

Local Authority	Number of responses
Aberdeen City Council	17
Aberdeenshire Council	20
Angus Council	23
Argyll and Bute Council	65
City of Edinburgh Council	35
Clackmannanshire Council	42
Comhairle nan Eilean Siar	30
Dumfries and Galloway Council	56
Dundee City Council	23
East Ayrshire Council	22
East Dunbartonshire Council	27
East Lothian Council	16
East Renfrewshire Council	52
Falkirk Council	24
Fife Council	34
Glasgow City Council	70
Inverclyde Council	203
Midlothian Council	20
North Ayrshire Council	15
North Lanarkshire Council	44
Orkney Islands Council	8
Perth and Kinross Council	65

Local Authority	Number of responses
Renfrewshire Council	127
Scottish Borders Council	36
Shetland Islands Council	14
South Ayrshire Council	5
South Lanarkshire Council	30
Stirling Council	52
The Highland Council	21
The Moray Council	16
West Dunbartonshire Council	33
West Lothian Council	32
Unknown	1

Although we received a reasonable number of responses from some of the larger towns and cities, we had less success in reaching large numbers of carers in some of the more rural areas of Scotland.

The majority of carers who responded to the survey (96%) were adult carers.

2% of the responses we received were from former carers or people who did not see themselves as carers anymore because the relative that they had been caring for had now gone into residential care. Of the 1,278 carers who responded to the survey, 524 provided additional information about their experiences of accessing support over the last 5 years, and in particular the experiences of accessing support since the pandemic.

This additional information from carers has provided some useful narrative about how the Carers (Scotland) Act is being implemented across Scotland.



96% of carers lived in the same local authority as the person(s) they cared for



**13%** of carers provided support to relatives or friends in more than one local authority



# Awareness of Carers (Scotland) Act

In April 2018, the Carers (Scotland) Act was introduced in Scotland. This legislation was the result of years of campaigning by carers and carer organisations and introduced several new and enhanced rights for carers in Scotland.

Out of the 1,270 carers who responded to the question about awareness of the Carers (Scotland) Act, 33% had never heard of this piece of legislation.



The number of carers who have some awareness of the Carers (Scotland) Act has been steadily increasing since 2018. When we first asked this question in 2018, only 16% of carers knew about the Carers (Scotland) Act; in 2023 this had increased to 29% of carers telling us that they knew about the legislation.

Although more carers appear to be aware of the Carers (Scotland) Act, they did express concern that the legislation is unlikely to make a real difference for them if it is not being understood and implemented in the way that it was intended by the authorities.

"Whilst Carers Act has good intentions in reality too much of it is open to local authorities understanding of it and how they choose to implement it."

"Having the rights is one thing. Getting your local authority to take your views into account is another." Carers told us that it can be difficult to understand what rights they have and to make sense of the legislation. This is particularly true for those who may not see themselves as carers, and for carers who may be at the start of their caring journey.

"Carers don't know their rights & generally don't have the time or patience to look into them or dejargon all the language used in the paperwork. The amount of times I've heard "you have to specifically ask for... or they won't do it" I shouldn't have to ask for anything, if it's part of the service or they are meant to do specific things then they should just do them."

"I think there needs to be more awareness of who is actually considered a carer as I had no idea this would even apply to me. I have no idea of the help that is available to me living with someone in addiction."

## Carers' Rights in 2023: Survey of carers in Scotland

their rights.

# **Carers' rights in Scotland**

The Carers (Scotland) Act provides carers with a number of rights to access information, advice and support for themselves.

These include:



## Carers' rights in Scotland



## The right to receive information and advice

Carers in Scotland have the right to information and advice to help them with their caring role. Local authorities are required to provide this service for all carers, and in most instances will commission local carers centres to deliver this.

- 1,264 carers responded to the question about the right to receive information and advice
- 78% of the carers who responded said that they understood or had heard of their right to receive information and advice.



How many carers had heard or knew about their right to receive information and advice?



The number of carers who are aware of their right to receive information and advice has been steadily increasing since we first asked this question in 2018, when only 47% of carers had some level of awareness of this right.

For many carers, the information and advice that they received from their local carers centre has been a lifeline for them, particularly during the pandemic when many other services and support that carers relied on were limited or temporarily shut down.

## "I have struggled since well before the 1st lockdown, with only my local carer's centre for support and help with anything."

### "I think the support and services we get from our local carers centre and HSCP Carers lead has been phenomenal over the past 3 years"

Carers told us that their carers centre is often the only place where they felt listened to and have their concerns and issues taken seriously.

"Carers centre are always helpful – but local authority and hospital staff never talk to us as carers."

"I always have a listening ear with the carers Centre, they are amazing. In terms of my local council, they have had no involvement with us apart from blue badge." However, some carers told us that it can be difficult to access information and advice from their local carers centre. This is because carers centres are generally only open during 'normal' business hours. This makes it difficult for carers who work during the day or have difficulty leaving home during the day due to their intense caring roles.

"Although the support offered by the local carers centre is good, it's not very flexible, ie activities for carers are rarely on when I can attend due to working and childcare as a single parent."

"Lots of carers support is on when I am at work. I do have a carer support person but I struggle to be proactive in accessing support when I have so little time available and we are just surviving each day as it comes."

Carers who are juggling multiple caring roles also told us that they find it difficult to access some of the support that is available from local carers centres.

"I am registered with carers centre but unless I contact them there is no contact made or offered. Unsure what they can offer only ever been offered a course but can't go on due to caring role of multiple people." The carers centre should be the first point of contact for carers in Scotland. However, when someone first takes on a caring role, they aren't always aware of the services and support available to them and are not always signposted to their local carers centre. Unfortunately, this means that a number of carers remain without support, until they reach a crisis point.

"I have been caring for my dad for 6 years and over the past 18 months also my husband. I accepted this as my responsibility and only when reaching breaking point I was referred by social worker to the carers centre for support. That has been a turning point for me I now feel I may have a future that enables me to have some enjoyment in life."





## The right to request an Adult Carer Support Plan or Young Carer Statement

The Carers (Scotland) Act states that an Adult Carer Support Plan or Young Carer Statement should be offered to anyone who is identified as a carer, or to anyone who meets the definition of a carer and requests one.



The Adult Carer Support Plan or Young Carer Statement is a conversation about the impact that the caring role is having on all aspects of a carer's life and helps to identify any support that the carer may require to help them with their caring role and to have a life alongside their caring role.

Adult Carer Support Plans or Young Carer Statements are often carried out by staff in local carers centres

or by social workers (or in some instances by both), depending on which local authority is responsible.

- 1,264 carers responded to the question about the right to request an Adult Carer Support Plan
- 66% of the carers who responded had heard of or knew about the right to request and adult carer support plan.



How many carers had heard or knew about their right to request an Adult Carer Support Plan?



• 705 carers responded to the question about the right to request a Young Carer Statement.



Have never heard of this

## More carers were aware of their right to request an Adult Carer Support Plan or Young Carer Statement now than they were five years ago. In 2018 only 38% of carers were aware of the right to request an Adult Carer Support Plan, and 31% were aware of the right to request a Young Carer Statement.

Despite the increase in awareness about Young Carer Statements, it is worth noting that nearly half of the carers who responded to the question this year had never heard of a Young Carer Statement. This suggests that perhaps more awareness raising at local and national level is needed to inform people about support that is available for young carers.

Carers told us that although they are aware of their right to request an Adult Carer Support Plan or Young Carer Statement, it is not always easy to get one from their local authority or carers centre.

### "I know about the carers assessment and have asked 2 different places for one but no one seems willing to actually do it."

### "I'm still waiting on an adult support plan, I've been asking for a year."

There is currently no statutory requirement to prepare an Adult Carer Support Plan or Young Carer Statement within a specific timescale (unless caring for someone with a terminal illness). This has meant that requests for Adult Carer Support Plans or Young Carer Statements are frequently ignored or delayed, and carers are unable to challenge this.

• 54% of carers had heard or knew about the right for young carers to request a Young Carer Statement.



How many carers had heard or

"The LA do not care about their legal duty. Having no timeline for completing the adult carer support plan allows the LA to push aside requests from carers.

"I've been on a waiting list for a carers assessment since Aug last year. I've contacted SWD for an update and no reply."

For carers who have completed an Adult Carer Support Plan or Young Carer Statement, the experience has at times been disappointing and has not always led to more or better support for the carer. The Adult Carer Support Plan or Young Carer Statement is supposed to be a meaningful conversation about the impact of the caring role for the carer, but carers told us that it just felt like another form filling exercise. In some circumstances, carers felt that the process just made them feel even less hopeful about their future.

"Sadly, carer support plans feel like a tick box exercise for legislation which does not directly benefit carers, feels as though services & local authorities focus on box ticking & completing these forms, taking much needed time away for this has replaced true support, empathy & help that carers need."

"I've had a review and a carers support plan – it was a waste of time. Paperwork exercise. Never got any help, it's never been reviewed and my own health has suffered as a result."

Feedback from carers also suggests that staff are not always well informed about the guidance and policy on preparing Adult Carer Support Plans and Young Carer Statements. For example, when it comes to Adult Carer Support Plans, it is the local authority where the cared for person lives which is responsible for preparing these for the carer ( even if the carer does not live in the same local authority)

"Even though I am registered as my parents carer I have never been approached to do an ACSP. I recently took the steps to do this myself as my situation is getting worse. It is confusing as I stay in a different local authority area I get this plan from my parents LA not my own."

In order for a carer to request an Adult Carer Support Plan, the person they are caring for does not need to have had an adult social care assessment. There are many circumstances where the person who requires care and support will refuse to seek statutory support from adult social care services. This should not hinder the carer from seeking support for themselves.

## "Was told that to access an Adult Carer Support Plan (and my carer budget), the person I care for has to be reassessed despite it being less than a year since the last reassessment."

Preparing an Adult Carer Support Plan or Young Carer Statement requires staff who are experienced in having outcome focused conversations with carers. Every local authority in Scotland is allocated funding each year through the Carers Act Implementation Funding to meet the requirements of preparing an Adult Carer Support Plan and Young Carer Statement. However, we know from our previous work in identifying how Carers Act Implementation Funding was used in 2017/18 and 2018/19 that the funding is not always used for this purpose. The current staff shortages and capacity issues within social work and carers centres has meant that staff are not always available to prepare or review the support plans.

"Although the carers centre referred me to Social Work, it has taken over a year for any assessment & even though it was carried out in November last year...it has still not been put into practice. Social Work are obviously more stretched than I could imagine...promising support & offering a lifeline 5 months ago seems cruel when I am still waiting"

"Asking for and getting a carers assessment is two different things, there's not enough social work staff to carry out the assessments." In 2021, further regulations were introduced to the Carers (Scotland) Act to ensure that anyone caring for someone with a terminal condition was prioritised and offered an Adult Carer Support Plan or Young Carer Statement within a specific timescale.

- 940 carers responded to the question about the right to have an Adult Carer Support Plan or Young Carer Statement completed within a specified timescale if caring for someone with a terminal illness.
- 37% of carers had heard or knew that if they were caring someone with a terminal condition that they would be prioritised for an Adult Carer Support Plan or Young Carer Statement within a specific timescale.

Did carers know that support plans need to be done within a specified timescale if they are caring for someone with a terminal condition?



There appears to be very little awareness of the timescales associated with preparing an Adult Carer Support Plan or Young Carer Statement for carers caring for someone with a terminal illness. This is perhaps not surprising as it is a relatively new amendment to the legislation.

It is important that people who are caring for someone with a terminal illness are made aware of their right to request an Adult Carer Support plan or Young Carer Statement as early as possible so that they can access vital support to help them with their caring role. However, feedback from carers suggests that carers of people with a terminal illness are not always being identified early enough.

"My experience of being a carer for a friend with a terminal illness was that only when he was admitted to the community hospital hospice bed did I receive contact with a carer support worker."

## Carers' rights in Scotland



# The right to access support if you meet the local eligibility criteria

If a carer has support needs that cannot be met through the support provided to the person they are caring for or through general local services, then under the Carers (Scotland) Act, the local authority has a duty to support that carer if they meet the local eligibility criteria for carers.

- 1,243 carers responded to the question about the right to access support if they meet the local eligibility criteria for carers.
- 52% of the carers had heard or knew of their right to access support if they met the local eligibility criteria for carers.



Have never heard of this

The number of carers who were aware of their right to access support if they met the eligibility criteria has increased since 2018 when only 39% of carers were aware of this right.

A number of carers told us that this right to access support was pointless because the local eligibility criteria is set far too high. This means that only carers who are considered to be 'critical' end up being offered any support at all. Carers who are on the verge of a crisis are often unable to access any support whatsoever.



How many carers had heard or that local authorities had a duty to support carers who met the local eligibility criteria?



"Despite being desperate at times, I have never reached the criteria for statutory support. It seems that the bar is set so high in order to serve the governments budget needs instead of the actual carer's needs. It is stressful, time consuming and intrusive to go through a carers assessment and carers do not have the capacity for additional stress or work. Then, when the outcome offers very little help, it adds to the hopelessness of the carer (well it did for me)."





Carers also told us that even if they met the threshold for the eligibility criteria, they were often unable to access support as they were told that there were no resources available in their local area.

"Social care services have not recovered since the pandemic. With needs at "substantial" on my adult carer support plan submitted in October 2021, I have not yet been offered Social Work support."



Carers also told us that there is no accountability in the system and that local authorities will ignore their duty to support carers, even if carers meet the eligibility criteria.

"I did an Adult Carers Support Plan which showed that I met the local authority's eligibility criteria but have received no support from the local authority and neither has the child that I am caring for."

"I have needs as identified in my adult carers support plan but I cannot get anything put in place to have them met. The plans are pointless without being practical too. I have a support plan but never get any help. Any time I ask I get told it's not available. No support for the young carers in my family either"



# The right to be involved in the care assessment of the person you are caring for

The Carers (Scotland) Act states that local authorities must consider the views of carers (as far as that is 'reasonable and practical') when assessing the needs of the person being cared for.

- 1,249 carers responded to the question about the right to be involved in the care assessment of the person they are caring for.
- 66% of the carers knew or had heard of their right to be included in discussions about the support needs of the person(s) that they care for.



How many carers had heard or knew that local authorities had a duty to support carers who met the local eligibility criteria?



The number of carers who were aware that they have the right to be involved in the care assessment of the person they care for, has increased since 2018, when only 48% of carers were aware of this right.

However, carers told us that even though health and social care professionals may include them in the discussions about the people that they care for, their views are very often dismissed and they aren't always seen as equal experts and partners in care. "When discussing the care and support of the person I care for, my views were dismissed, and I was told it was between the professional and the person I care for."

"I have a right to be listened to but the adult mental health services don't appear to think I do, or maybe I have a right to be heard but they minimise, discount and don't take notice of my view. Our situation is exacerbated by living across a local authority boundary."



# The right to be involved in the hospital discharge planning of the person you are caring for

The Carers (Scotland) Act states that each health board must ensure that carers are involved in the hospital discharge planning of the person that they are caring for, or plan to care for.

- 1,254 carers responded to the question about the right to be involved in the hospital discharge planning of the person they are caring for.
- 69% of the carers in our survey had some knowledge of their right to be included in discussions around the hospital discharge of the person that they are caring for.



Carers' awareness of their right to be included in hospital discharge discussions has been steadily increasing since we first asked this question in 2018.

However, despite being aware of this right, carers told us that they are rarely included in the hospital discharge discussions about the person they care for.



How many carers had heard or abou their right to be included in the hospital discharge planning of the person they are caring for?



"Hospitals still do not fully understand what carers rights are they do not always include them when making plans or take notice of their concerns."

"Whilst I have the right to be involved in the discharge of my caree the hospitals are not great at complying." When carers are not included in the discharge planning discussions, it can often lead to hospital discharge plans that do not take into account the specific needs of the patient or carer.

"On several occasions I flagged up issues re coping at home but because he could cope in hospital that was all that mattered. There needs to be much more involvement of carers and particularly when adult is younger, ie cannot access care for elderly."

On occasions when carers have asked to be included in the hospital discharge discussions, the requests have been outright denied.

"When the person I care for has been in hospital I have never been invited to be involved in any discussion around their discharge. Indeed, on one occasion when we tried it was made clear to us that our input was neither welcome nor listened to."

"I asked to be at a meeting re discharge from hospital but that was declined."







# The right to be involved in the planning of local carer services

The Carers (Scotland) Act states that local authorities and health boards must involve carers in planning the carer services they provide, and must consider the views of carers and carer representatives when preparing and reviewing carer strategies and policies.

- 1,249 carers responded to the question about the right to be involved in the planning of local carer services.
- 60% of the carers knew or had heard about their right to be involved in the planning of local carer services.



An increasing number of carers are now aware or have some knowledge of their right to be included in the planning of local carers services. In 2018 only 39% of carers were aware of this right; this year it increased to 60%. Nevertheless, carers told us that decisions about local carer services and policies are still being made without fully involving carers in the local decision making process.



How many carers had heard or knew about their right to be included in the planning of local carers services?



"We have no-one in post for Adult Carers support in our local authority and haven't for some time. Information is not filtered down or shared widely, and we haven't been well represented in groups. The authority is making decisions and deliberately not involving Carers, eg, in respite allocation."

# Making rights a reality for carers

It has been five years since the Carers (Scotland) Act was introduced. The legislation included a number of new and enhanced rights for carers. The findings from this survey suggest that carers in Scotland are far more aware of their rights in 2023 than they were five years ago. However, many of these rights are not actually being realised in practice.



For example:

- Not all carers are able to access the information and advice services that are available locally
- Many carers are waiting too long for an Adult Carer Support plan to be completed
- Carers who are caring for someone with a terminal condition aren't always identified and offered support early enough.
- High thresholds for Local Eligibility Criteria are preventing carers from accessing statutory support unless they are in crisis
- Carers are not always given the opportunity to be involved in discussions around hospital discharge planning
- Carers are not being fully included in the design and development of local carer services and policies
- Staff are not always aware of the rights that carers have to access information, advice and support.

Having knowledge and awareness of carers rights is important. But for those rights to be realised, duty bearers need to take more responsibility for respecting and protecting those rights.

Duty bearers include the Scottish Government, local authorities, health boards, and organisations who are commissioned to support carers.

One of the ways in which duty bearers can ensure that they are implementing and embedding carers' rights in their policies and practices is by adopting a more Human Rights Based Approach to supporting carers. This involves incorporating five human rights principles:

- Participation
- Accountability
- Non-discrimination and equality
- Empowerment
- Legality

Collectively these are known as the PANEL Principles<sup>4</sup> and can be used as a starting point for organisations to evaluate how well they are doing in terms of respecting, promoting, and protecting the rights of carers.

Ρ	Participation	Carers are involved in a meaningful way in decisions that will affect them or the people that they are caring for
A	Accountability	Transparency about how carer policies are implemented and carers should know who they can contact if their rights are not being realised
Ν	Non-discrimination and equality	All carers (regardless of their protected characteristic) are able to access information, advice and support to help them in their caring role
Е	Empowerment	Carers are supported to take an active role in developing policy and practices which affects them. This includes support to participate in decision making forums
L	Legality	Approaches to support carers should be compatible with legislation such as: Carers (Scotland) Act 2016 and Social Care (Self- directed support) Act 2013

4 https://www.scottishhumanrights.com/projects-and-programmes/human-rights-based-approach/

# Recommendations

Based on the feedback from carers in our survey, we have outlined some recommendations to address the current gaps that exist in making carers rights a reality. Some of the recommendations apply to all duty bearers who have a responsibility to protect and uphold the rights of carers, whereas other are targeted specifically at local authorities, health boards, carers centres, or the Scottish Government.

## **Participation**

Carers should be involved in meaningful way in decisions that affect them or the people that they care for.

## Health Boards/HSCP:

 Review current policy and practice to ensure that carers are included in discussions about hospital discharge planning for relatives or friends that they are caring for.

### Local authorities/HSCP:

• Review current policy and practice (in line with EPiC principles) to ensure that the views of carers are included during social care assessments of supported people.



## Accountability

Duty bearers should be aware of their responsibilities to protect carers rights, and be transparent about how carers can challenge practices and policies if their rights are not being respected.

### All duty bearers:

- Ensure carers are informed of who they can contact if they are unhappy about local carer services and support.
- Ensure that staff are aware of their responsibility to implement and protect carers' rights.



# Non-discrimination and equality

A carer's protected characteristic and caring circumstances should not be a barrier for them to access support.

### Health Boards/HSCP:

• Information about a carer's right to be involved in hospital discharge planning should be made accessible to all carers.

### Local authorities/HSCP/Carers Centres:

- Information and advice services should be fully resourced to ensure that it is accessible and inclusive to all carers, regardless of their protected characteristic or caring circumstances.
- Adult Carer Support Plans and Young Carer Statements should be offered to any carer that requests it (and shouldn't be restricted to only carers who access local carers services).
- Information for carers who are looking after someone with a terminal illness should be more widely publicised.



## **Empowerment**

Carers should be supported to take part in developing policies and practices that affect them.

#### All duty bearers:

• Promote training and mentoring opportunities for carers to get involved in local and national Carer Planning/Strategy groups.

#### Local authority/HSCP:

 Support carers to be involved in the development of local carer strategies, local eligibility criteria, and short breaks statements.



## Legality

All carer policy and practice should be compatible with the Carers (Scotland) Act.

## All duty bearers:

- All staff should have a good understanding of the legislations which underpin the rights that carers in Scotland have.
- Ongoing training should be made available to staff to understand their responsibilities to respect and protect the rights that carers have.





from recognition to rights

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