mental welfare
commission for scotland

Not on the radar

A themed report on the experience of carers

Themed report

October 2025

Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

Contents

Foreword - Julie Paterson, chief executive

The title ‘Not on the radar’ painfully captures the reality of Scotland’s carers. These are the voices we don’t hear often enough, despite carers being central to the wellbeing of so many living with mental illness, learning disability, dementia, and related conditions.

Carers are not just support networks or resources. They are parents, children, partners, and siblings. They are people who shoulder enormous responsibility, often without thanks or recognition, and sometimes at the cost of their own health, financial security, and peace of mind.

This work was guided by our advisory committee, which includes people with experience of using mental health services and of caring. We wanted to go beyond assumptions and listen directly to carers about what is working, what is not, and how they feel about the systems they rely on. Over 370 carers and 109 service practitioners responded to our questionnaires, and some carers joined online sessions to speak with us directly. Their honesty and openness have shaped this report, and we are grateful.

What was shared was not easy to hear. Many carers spoke of feeling excluded from vital decisions about their loved one’s care. Others described how hard it is to get basic information, or how frustrating it is when services assume they are involved—when in fact, they are not. A significant number told us they had been caring for decades, often feeling invisible and alone.

While 85% of services told us they provide carers with health and wellbeing support, only 33% of carers experience it. Half struggle to share or receive information about their loved ones, and transitions between services—particularly for young people moving from child to adult mental health care—often disregard carer input. There is a clear need to bridge the gap between intention and lived experience.

In this complex landscape, we make one core recommendation: that carers be recognised as equal partners in care. Not just in theory, but in everyday practice—with clear rights to information, meaningful involvement in care planning, and provided with necessary support.

The Scottish Government’s vision for enabling people to live longer, healthier, and fulfilling lives must extend to carers. Their wellbeing is not a lower priority; it is foundational to Scotland’s health and social care future.

Legislation alone cannot heal burnout but supported by the right resources and with carers valued as experts, we can transform ‘not on the radar’ into ‘central to our mission.’

Introduction

The Mental Welfare Commission for Scotland (the Commission) undertakes national themed visits that report on either particular themes or groups that impact on the care and treatment of people across Scotland.

Throughout our work, we keep returning to the role of family, carers, those important to people with a diagnosed mental illness, learning disability, dementia and related conditions and the barriers and challenges faced by them.

The Carers (Scotland) Act 2016 was implemented in 2018 and defines young carers and adult carers and sets out their rights to support, information and inclusion. The Commission's good practice guide titled *Carers, consent and confidentiality* (updated in 2024) emphasises the importance of carers knowing their rights when navigating health, social work, and social care services. The Scottish Mental Health Law Review (SMHLR) published in 2022 made four recommendations further underlining the important role carers fulfil to support, protect and advocate for those who experience mental illness, learning disability, dementia and related conditions. Yet, barriers remain and indeed Carers Scotland in their report *State of Caring in Scotland 2024* highlight a growing mental health crisis within Scotland's unpaid carer population itself.

Whilst we regularly engage with carers across Scotland through our visiting programme, through our engagement and participation team and through long established links with Carers' Centres, we wanted to undertake this themed visit approach to develop a more in depth understanding of the experience of those who care.

Given the fiscal challenges, delayed discharges and finite community social care support, there is concern that the long standing reliance on unpaid carers to supplement and complement existing provision of support is shifting to be the only available support….at the expense of the carer's health and wellbeing and at the expense of other key roles of parent, partner, sibling, son or daughter which are disappearing in the midst of the all-consuming caring role.

> *"Being an unpaid carer has affected every aspect of my life.*
> *I have never just been able to be in the role of 'mum'".*

Background

Publications and reviews

The Carers Week Report (2025) *Caring about Equality* estimated that 716,250 people are currently providing unpaid care in Scotland. This estimation is slightly higher than the number identified in Scotland's Census 2022, which had a figure of 627,700.

The research from the report looked into the impacts of caring for current and former carers, explored the disadvantages that carers felt that they faced and specifically looked at key health and wellbeing issues. Findings were based on an independent survey of 2,000 people in the UK, aged 18 and over.

The results found that a significant number of carers were struggling with their own health and wellbeing. Carers raised the issue of not always being able to take a break to look after their own health, with a high proportion of carers having cancelled medical appointments due to the demands of their caring role. They also reported a reduction in social networks, financial disadvantage due to having to reducing working hours and not getting the support they needed.

The Carers Week report built upon the earlier findings of Scotland's 2023 Carers Trust report, a summarised version of which was powerfully titled, *"Unpaid carers are not unsung heroes. We are forgotten, neglected and burnt out"*.

The Carers Trust Scotland's report called for the Scottish Government to fully implement the National Carers Strategy Action Plan, which was detailed in the 2022 National Carers Strategy.

There have been more than ninety supportive carer-related recommendations made in recent years, with statements about the vital role of unpaid carers and how their value cannot be overstated. Whilst the Commission meets carers and relatives as part of our day to day work we were keen to undertake a focussed piece of work to learn what has in fact changed for carers as a result of the various recommendations made and to what extent have they realised their rights. Is Scotland now that "place where all carers are recognised and valued for the contribution they make, where they are enabled to provide the right support for the people they care for while living full, rounded lives"? (Kevin Stewart, Minister for Mental Wellbeing and Social Care).

Overview of the report

Methodology (what we did)

The Commission's advisory committee is a statutory standing committee of our Board and consists of representatives from 31 organisations from across Scotland. This advisory committee, chaired by our Board members with experience of using mental health services and experience of caring helped to shape some of the focus of this themed piece of work alongside our engagement and participation manager who has direct experience as a carer.

Four key areas were explored and are considered in this report:

- Involvement of families and carers (Chapter 1)
- Getting information about a relative who is receiving health care and support (Chapter 2)
- Responsibilities of staff/services to engage with and support families and carers (Chapter 3)
- Transitions: moving between services (Chapter 4)

We developed questionnaires using MS Forms. Questionnaires for carers included demographic information such as age, gender, ethnicity and postcode; this was to help us understand where respondents lived in Scotland. The carer questionnaire was open from 19 December 2024 to 3 February 2025 and was promoted through emails to individuals who were in contact with specific carer services and organisations.

We received a total of 371 questionnaires completed by carers.

Having reviewed the results from the carer questionnaires (there was little response from young carers), we were able to provide an initial overview of some key findings and presented these to carers for further discussion in a series of Zoom sessions held in March 2025. A total of 29 carers attended these Zoom sessions.

A separate Zoom session was held in April 2025 with workers who support young carers to try to get a sense of the particular issues young people face.

An online service questionnaire was developed and sent to staff in health services across Scotland. Our focus was on mental health and learning disability specific health services rather than social work service provision which is not always underpinned by diagnostic criteria.

The questionnaire that was sent to practitioners in health services echoed the themes of the carer questionnaire, and this was open from 24 February to 24 March 2025.

We received a total of 109 responses from service practitioners.

Demographic information

371 people responded to our carers questionnaire; over half were 45-64 years and a third older than 65 years. We know from speaking to older carers that they fear what will happen to the person they support if they are no longer well enough or around to do so. Unfortunately, only three people under the age of 25 years responded to our call for views.

Young carers are a particularly hidden group and this work has not been able to capture their specific challenges. We know that young people often support their parents or siblings with fluctuating mental illness, provide ongoing care for siblings with learning disability and this impacts their ability to participate fully at school and in social activities/peer relationships.

Chart 1: age range of carer responses

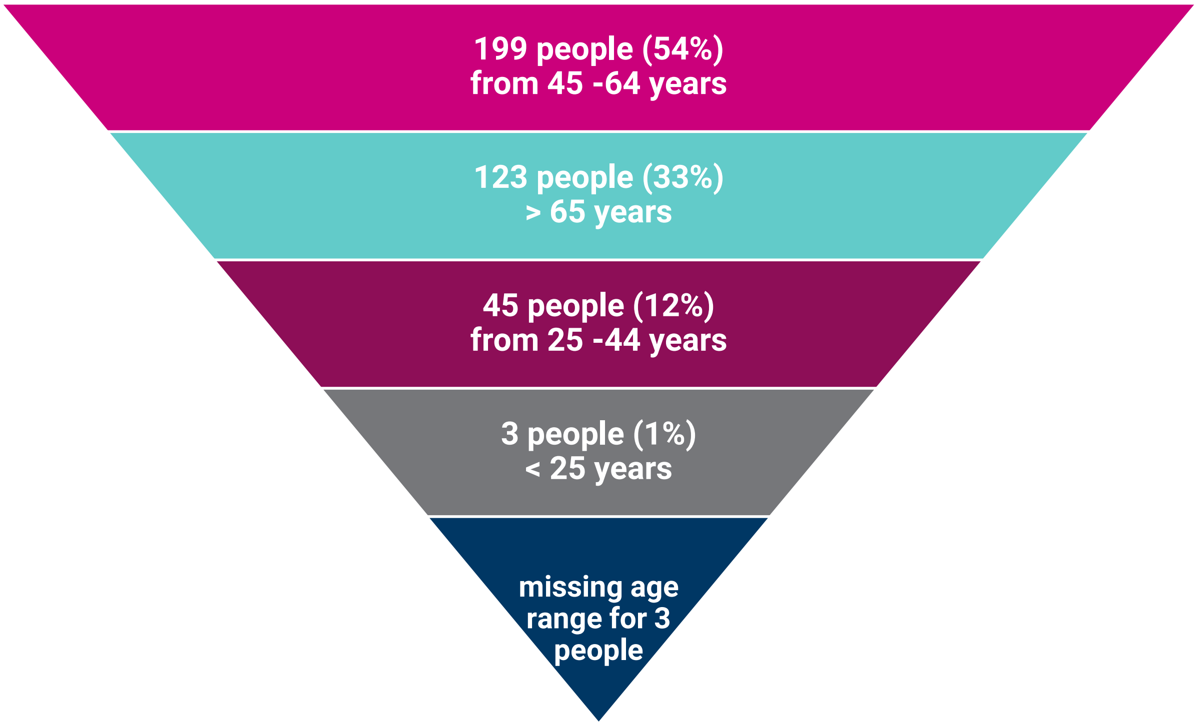
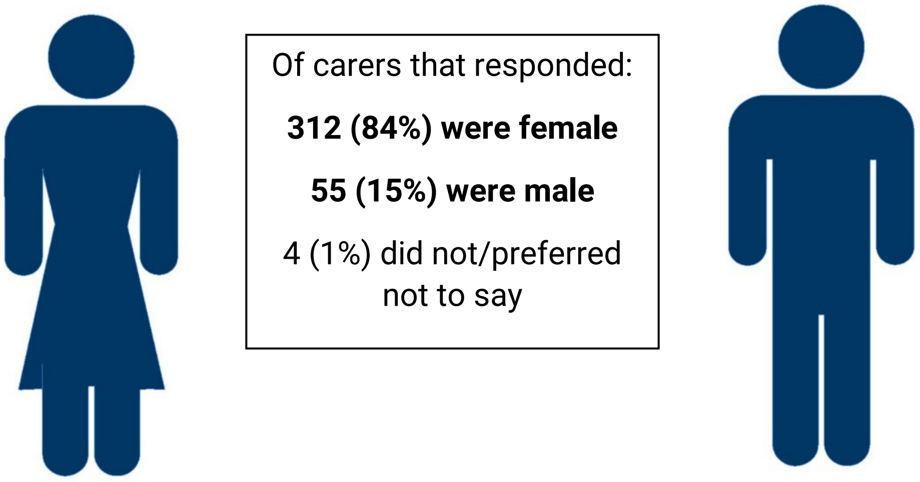


Figure 1: gender split of carer responses



Of carers that responded:

312 (84%) were female

55 (15%) were male

4 (1%) did not/preferred not to say

The table below shows the characteristics of people who responded to the carer questionnaire, most of whom described themselves as White Scottish with no particular significance arising from the SIMD (level of deprivation) data.

We directed our questionnaires to health boards and in these questionnaires we asked respondents to tell us which health and social care partnership they worked in. We noted that responses were higher from Edinburgh City (Lothian health board), Fife (Fife health board) and East Renfrewshire (Greater Glasgow and Clyde health board). There were three health and social care partnership areas where no responses were received – East Ayrshire, Eilean Star and the Shetland islands. In eight responses (2%) the health and social care partnership area was missing from the completed questionnaire.

Table 1: Respondent characteristics for carer questionnaire

Category	Range	n	(%)
SIMD		371	
	1-most deprived	42	(11.3%)
	2	56	(15.1%)
	3	56	(15.1%)
	4	84	(22.6%)
	5-least deprived	91	(24.5%)
	Not Found	8	(2.2%)
	Only partial postcode given	34	(9.2%)
Ethnicity		371	
	African, Scottish African or British African	≤3	(≤0.8%)
	Any other Asian	≤3	(≤0.8%)
	Any other white ethnic group	9	(2.4%)
	Chinese, Scottish Chinese or British Chinese	≤3	(≤0.8%)
	Indian, Scottish Indian or British Indian	≤3	(≤0.8%)
	Mixed or multiple ethnic group	≤3	(≤0.8%)
	Other	4	(1.1%)
	Pakistani, Scottish Pakistani or British Pakistani	4	(1.1%)
	White Irish	4	(1.1%)
	White Other British	56	(15.1%)
	White Polish	≤3	(≤0.8%)
	White Roma	≤3	(≤0.8%)
	White Scottish	280	(75.5%)
	Missing	4	(1.1%)
Health Board		371	
	NHS Ayrshire and Arran	6	(1.6%)
	NHS Borders	7	(1.9%)
	NHS Dumfries and Galloway	22	(5.9%)
	NHS Fife	49	(13.2%)
	NHS Forth Valley	32	(8.6%)
	NHS Grampian	43	(11.6%)
	NHS Greater Glasgow and Clyde	52	(14.0%)
	NHS Highland	14	(3.8%)
	NHS Lanarkshire	11	(3.0%)
	NHS Lothian	97	(26.1%)
	NHS Orkney	8	(2.2%)
	NHS Shetland	0	(0.0%)
	NHS Tayside	26	(7.0%)
	NHS Western Isles	0	(0.0%)
	Missing	4	(1.1%)

Carers' description of their role

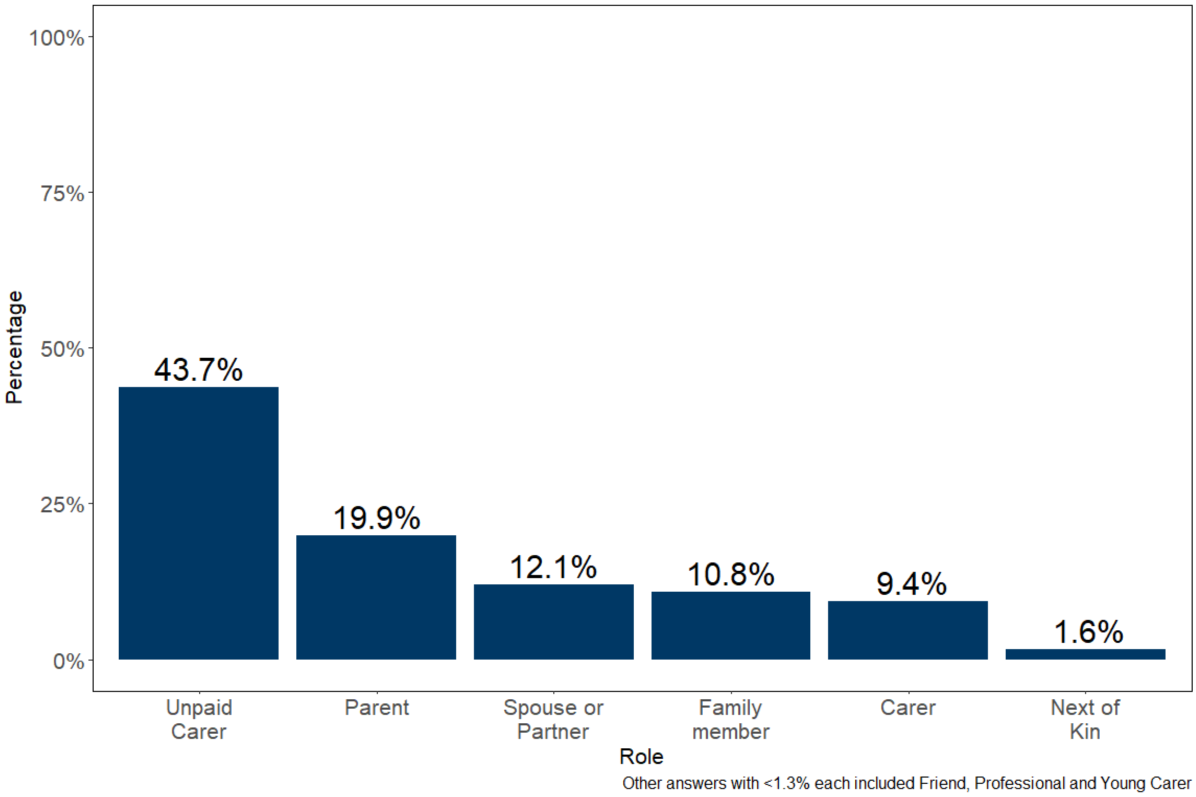
162 people (43.7%) who responded to our questionnaire said that they were an unpaid carer, with a further 35 (9.4%) defining their role as carer.

Almost as many respondents did not describe themselves as a carer (n=165, 44.4%). Instead, they described themselves as a family member (10.8%, n=40, 10.8%), next of kin (n=6, 1.6%), a parent (n=74, 19.9%) or a spouse or partner (n=45, 12.1%). Another term that was used was 'parent carer'.

We also had a small number of people who said they were professionals, friends, young carers or this response was missing (n=9, 2.4%).

We know the limitations of definitions as often people tell us it is 'just what they do'; it's their job to support and take care of the people important to them. We are also grateful to respondents recognising that participation in these questionnaires is challenging while all other responsibilities are being juggled.

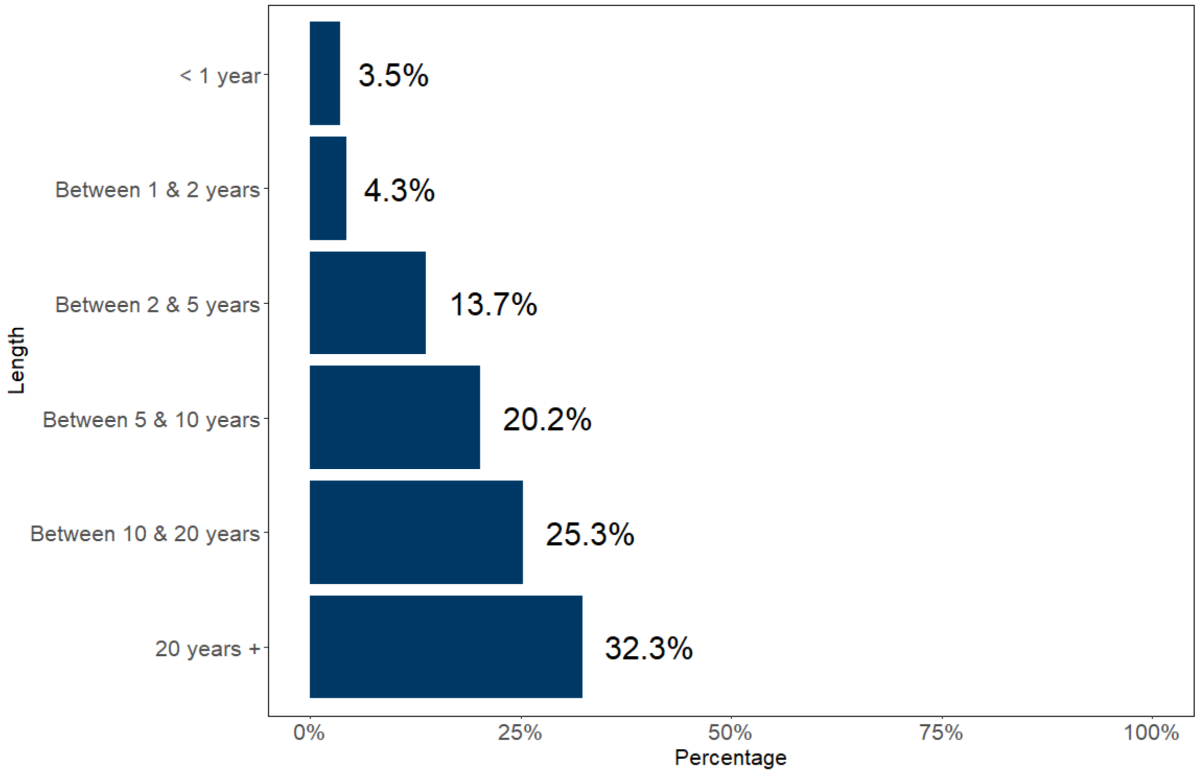
Chart 2: how people responding to the carer questionnaire described their role.



240 (64.7%) respondents said they lived with the person they cared for while 124 (33.4%) did not. Seven people (1.9%) did not complete this question.

289 (77.8%) respondents reported undertaking their caring role for more than five years with 120 (32.3%) having fulfilled the role for more than 20 years. There is no doubt that caring is a long-term commitment for those who participated in this themed work.

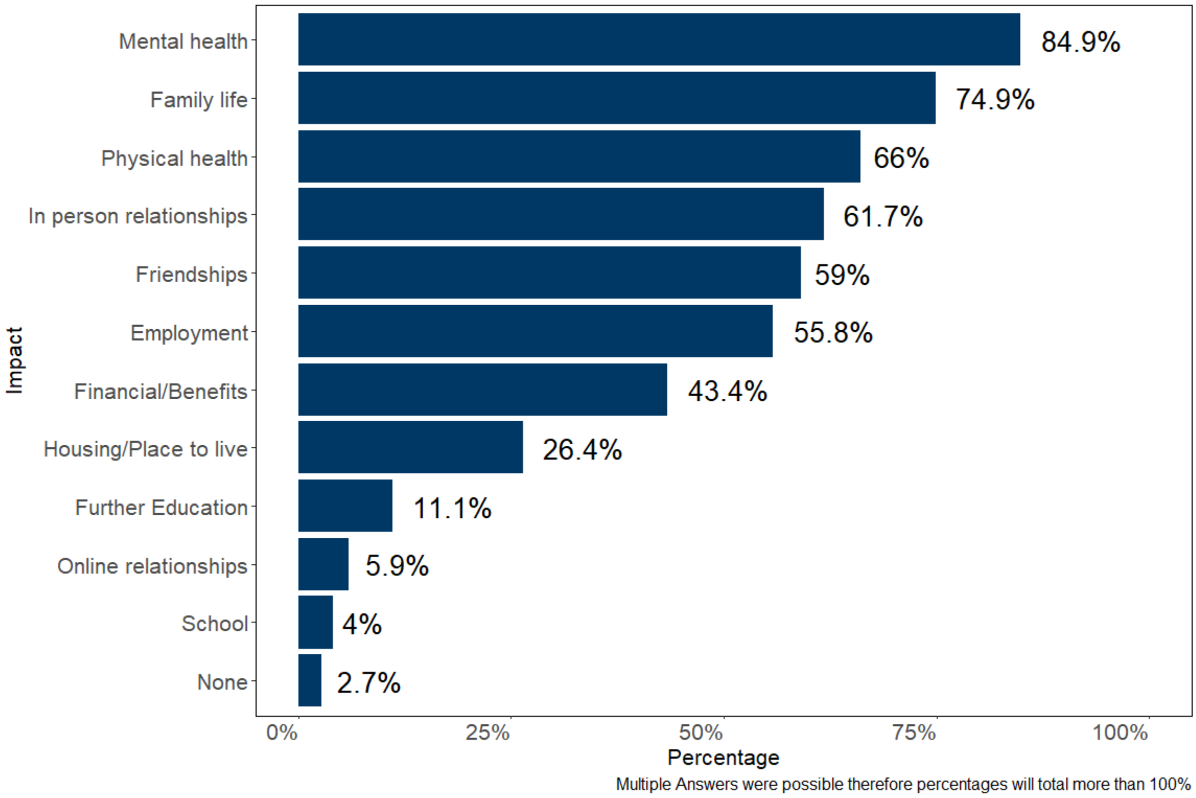
Chart 3: length of time as a carer



We were missing information in n=2 cases

Finally, for this section of the questionnaire, we asked people to tell us if their caring role had an impact on aspects of their own life. Respondents could tick as many responses as they wished. We also received 93 additional comments from carers in this section highlighting the unique role and experience of each.

Chart 4: area where carers have been affected by the impact of caring



The impact of caring is wide reaching as noted in chart 4.

The focus of our themed work was on caring for people with mental illness, learning disability, dementia and related conditions. It is significant that those caring, in turn, report the fragility of their own mental health as a result (84.9%). Figure 2 below shows the multiple challenges faced with over 50% of carer respondents experiencing impact on their mental health, on their physical health and on their family life.

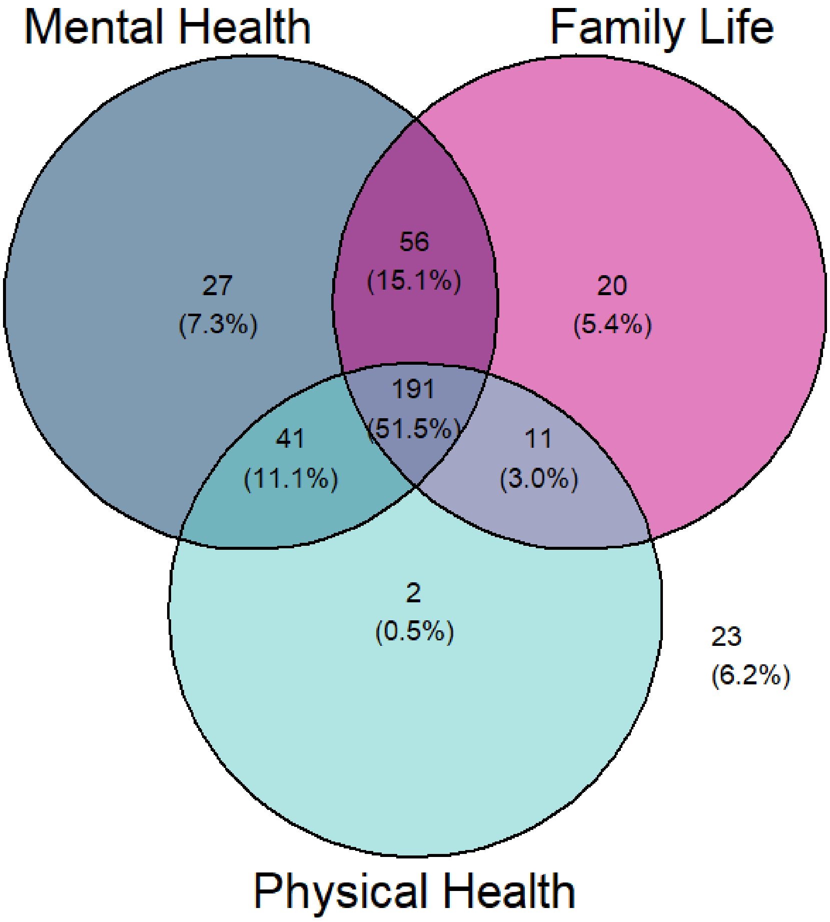
We heard:

> *"It is getting harder and I am physically and mentally exhausted.*
> *Some of it is due to caring, and our situation, and some due to ill health.*
> *But we will carry on, fingers crossed, grateful for*
> *the small wins and some good days."*

and:

> *"My own health and personal situation has faced*
> *some deterioration directly as a result of this.*
> *My own healthcare needs go largely side-lined*
> *as I don't trust the NHS to care for me."*

Figure 2: the impact and overlap on carers' lives



There were many comments highlighting the financial impact of caring:

> *"And because my government pension is so pitiful and*
> *I am an unpaid carer I cannot afford to take courses or have fun.*
> *The term unpaid carer just really equals slave."*

and:

> *"This obviously affected me financially at the time but has a lasting impact*
> *as I stopped paying into a private pension scheme for 15 years*
> *and I'll have to keep working until I reach state pension age".*

Key points

- While the majority of respondents to our questionnaire indicated that they were either unpaid carers or carers, there were still nearly half who did not describe themselves in this role; instead they were a family member, or a next of kin, a parent (or parent carer) or partner.
- The majority lived with the person they cared for, they had been doing this for at least 5 years or more, and significantly, nearly 85% of people who answered our question on the impact on them noted that it had affected their mental health.

Service demographic information

We asked managers and/or leads across the health board areas what type of services they worked in. The 109 respondents told us of the clinical focus of their area, their health board and the health and social care partnership area (HSCP) they covered.

Table 2: clinical services of service respondents

	Level	**n (%)**
Service Type*		
	CAMHS - in-patient	≤3 (≤2.8%)
	CAMHS - community	16 (14.7%)
	Adult (under 65) - in-patient acute admissions	19 (17.4%)
	Adult (under 65) - community	13 (11.9%)
	Adult (under 65) - rehabilitation	8 (7.3%)
	Adult (under 65) - speciality ward	5 (4.6%)
	Older Adults - assessment	7 (6.4%)
	Older Adult-in-patient MI	9 (8.3%)
	Older Adult -in-patient Dementia	16 (14.7%)
	Older Adult-in-patient Longer Term Care	7 (6.4%)
	Older Adult – community	8 (7.3%)
	Forensic	11 (10.1%)
	Specialist Learning Disability	4 (3.7%)
	Specialist Addiction Services	8 (7.3%)
	Prisons	≤3 (≤2.8%)

**Services can provide multiple types of services therefore totals will add to more than n=109.*

Table 3: respondents by Health Board area

Health Board*		n	(%)
	NHS Ayrshire and Arran	≤3	(≤2.8%)
	NHS Borders	≤3	(≤2.8%)
	NHS Dumfries and Galloway	0	(0.0%)
	NHS Fife	7	(6.4%)
	NHS Forth Valley	≤3	(≤2.8%)
	NHS Grampian	12	(11.0%)
	NHS Greater Glasgow and Clyde	25	(22.9%)
	NHS Highland	22	(20.2%)
	NHS Lanarkshire	0	(0.0%)
	NHS Lothian	34	(31.2%)
	NHS Orkney	≤3	(≤2.8%)
	NHS Shetland	≤3	(≤2.8%)
	NHS Tayside	8	(7.3%)
	NHS Western Isles	≤3	(≤2.8%)

**Services can cover more than one Health Board area therefore totals will add to more than n=109*

For the service questionnaire, we heard from staff working across all of the age ranges, from child and adolescent mental health services (CAMHS) to older adults. We heard from staff working in both mental health and learning disabilities services. There were no staff responses from Dumfries and Galloway or Lanarkshire.

Limitations

While the data we have received as part of this work is rich and significant, it is also important to note the limitations of our methodology. For example, self-reported data cannot be independently verified and can contain potential bias sources. Use of methods such as questionnaires and focus groups have the potential to limit the diversity of data. For example, we know that people from the most deprived areas are three times more likely to be hospitalised for mental health issues than those in wealthier areas. The SIMD information (table 1) notes only 11.3% of respondents to this themed work come from the most deprived areas.

Chapter 1: Involvement of carers and families

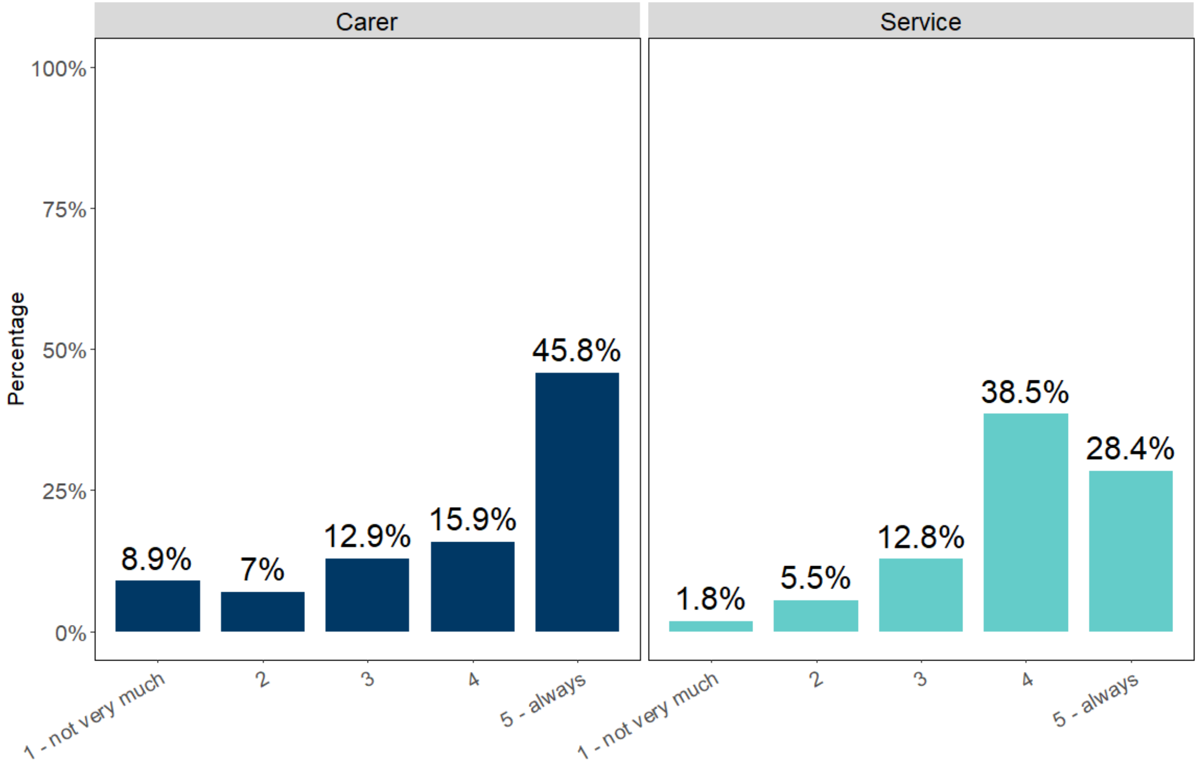
What we expect

We expect staff to have a clear understanding of their responsibilities to families. Whilst it is right that consent should be sought from patients/individuals to share information with others, this should not act as a barrier to listening to the concerns of carers who may be family members, next of kin and other people important to the person; and where possible involving them in care planning and safety planning. Staff must listen to carers and family members because they know the person and they have knowledge of the person's journey through mental health and learning disability services. The Commission's investigation into the death of Mrs F highlighted what can happen when family members are not listened to. We all need to learn from this tragedy and to consider carers, in whatever role they have in a family, as an invaluable source of information to optimise care, treatment and support.

What we found

We asked carers and services about carer and family involvement. We used a scale from 1-5 where 1 was not involved very much to 5 where carers and family members were completely involved in the care and treatment of the person they cared for. The responses are in chart 5 below.

Chart 5: Comparison between carers' and services' assessment of involvement



It should be noted that for some carers, they commented that the reason for scoring a 5 was that they were the only one involved in providing for the person they cared for.

20 respondents told us the person they cared for was currently in hospital. We were keen to learn about carer engagement at key points of hospital care. See table 4 below.

Table 4: carer involvement in hospital settings

	Level	**n**	**(%)**
Hospital Involvement*		20	
	Admission process	5	(25.0%)
	Care Planning	5	(25.0%)
	MDT Reviews	5	(25.0%)
	Discussion with key workers	5	(25.0%)
	In-patient reviews	6	(30.0%)
	Discharge planning	≤3	(≤15.0%)
	Risk assessments	≤3	(≤15.0%)

**Multiple answers possible to total which is greater than n=20*

We asked the same question where the person cared for did not live with the carer but was supported by community services. The 16 respondents told us:

Table 5: carer involvement in community settings

	Level	**n**	**(%)**
		16	
Community care involvement	Ongoing support by health professionals	5	(31.3%)
	Informal reviews	5	(31.3%)
	Formal reviews	8	(50.0%)
	Care planning	6	(37.5%)
	Medication changes	7	(43.8%)
	Risk assessments	6	(37.5%)

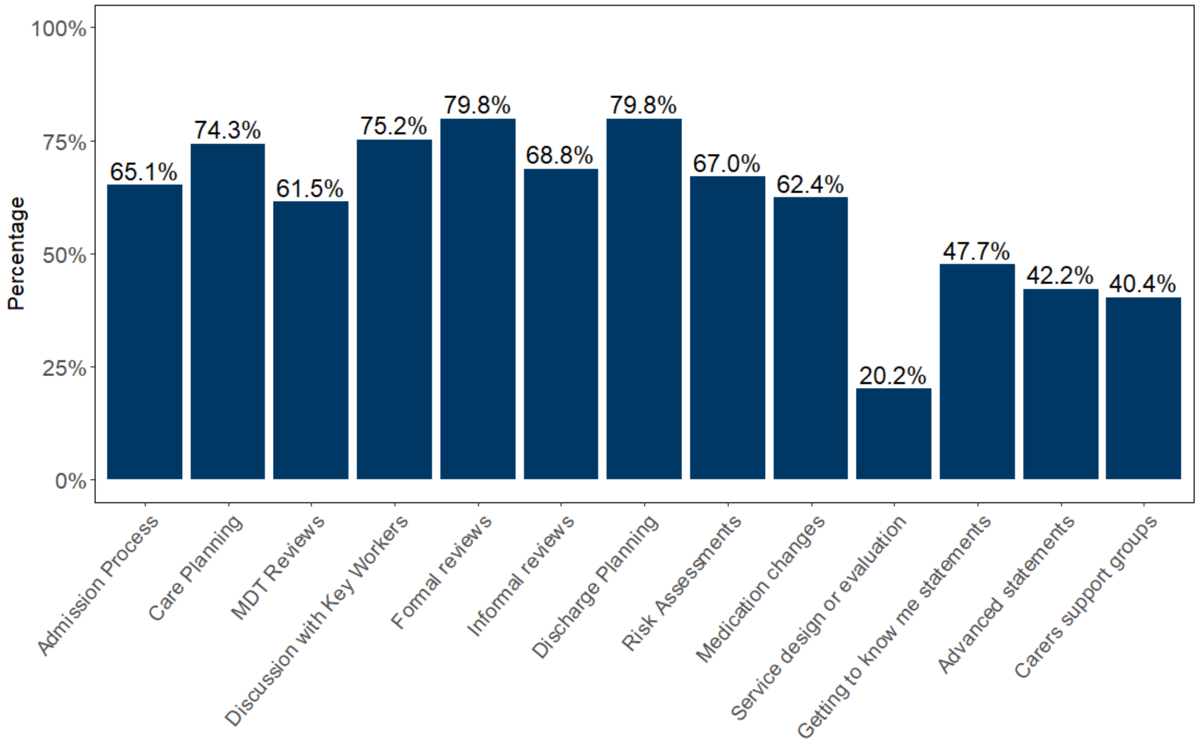
**Multiple answers possible to total is greater than n=16*

The Zoom sessions we held highlighted many frustrations:

> *"Carers are often advocating for their cared for person*
> *and this can be seen as 'moaning' where there are shortcomings.*
> *We have carers who have to give advance notice*
> *of their intention to attend appointments*
> *(in order to have an appropriate room)*
> *who are then told that they cannot go in the appointment.*
> *They perceive this as exclusion."*

As well as asking carers about the opportunities for them to be involved, we asked services their views. Services that responded to us said that they involved the carers in many aspects of treatment and care as noted below.

Chart 6: what aspects the service involves carers in



Some services provide more than one opportunity for involvement therefore the total will add to more than 100%

Other areas that services said they involved carers in were at informal reviews, in the young carers statement, when there was stress or distress, while assessing or information gathering or only when the individual/patient consents to this. Services told us that involvement was:

"Only with explicit consent of the client."

"Involvement sometimes depends on the age of the young person and if they consent for parents/carers to be involved in their care or discussions."

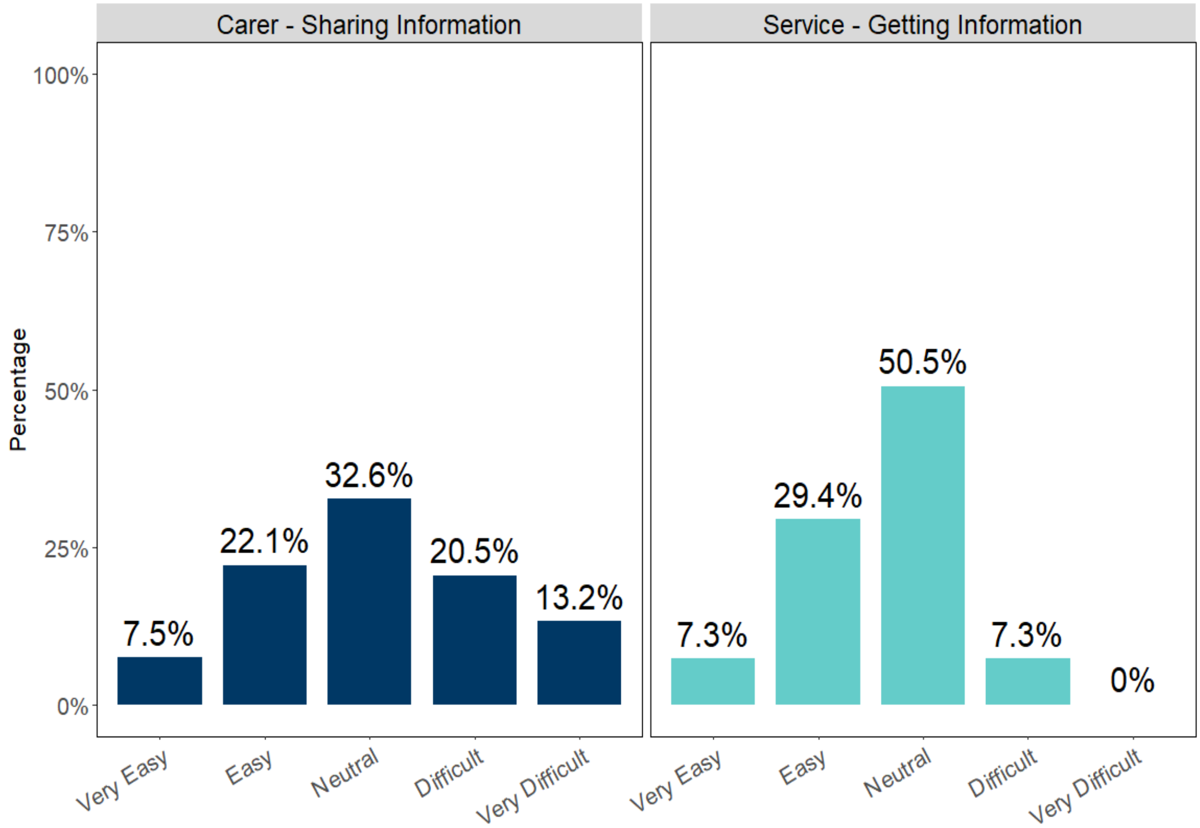
Information from carers

We asked carers, on a scale of very easy to very difficult, how they found sharing information about the person they care for. There was a mixed response, with 110 people (29.6%) telling us that it was easy or very easy to share information, although slightly more carers (n= 125, 33.7%) said it was difficult or very difficult.

We asked those in the service the question about getting information from carers. The scores for getting information easily from carers were broadly similar, but the main difference was in the scores where they found it difficult. Unlike carers, only 8 services (7.3%) said that that they had had difficulties getting information.

Families should always be allowed and encouraged to offer information to professionals involved. They know the individual best and can provide valuable information that does not breach the confidentiality of the relationship between the individual and the professional team.

Chart 7: comparing carers' and services' views on sharing/getting information



Maintaining relationships

We asked carers if, in general, staff provided them with the support to maintain the relationship between themselves and the person they care for. We wanted to know how frequently this had happened and we gave them a scale to measure from it always being the case that staff had supported the relationship to it never happening.

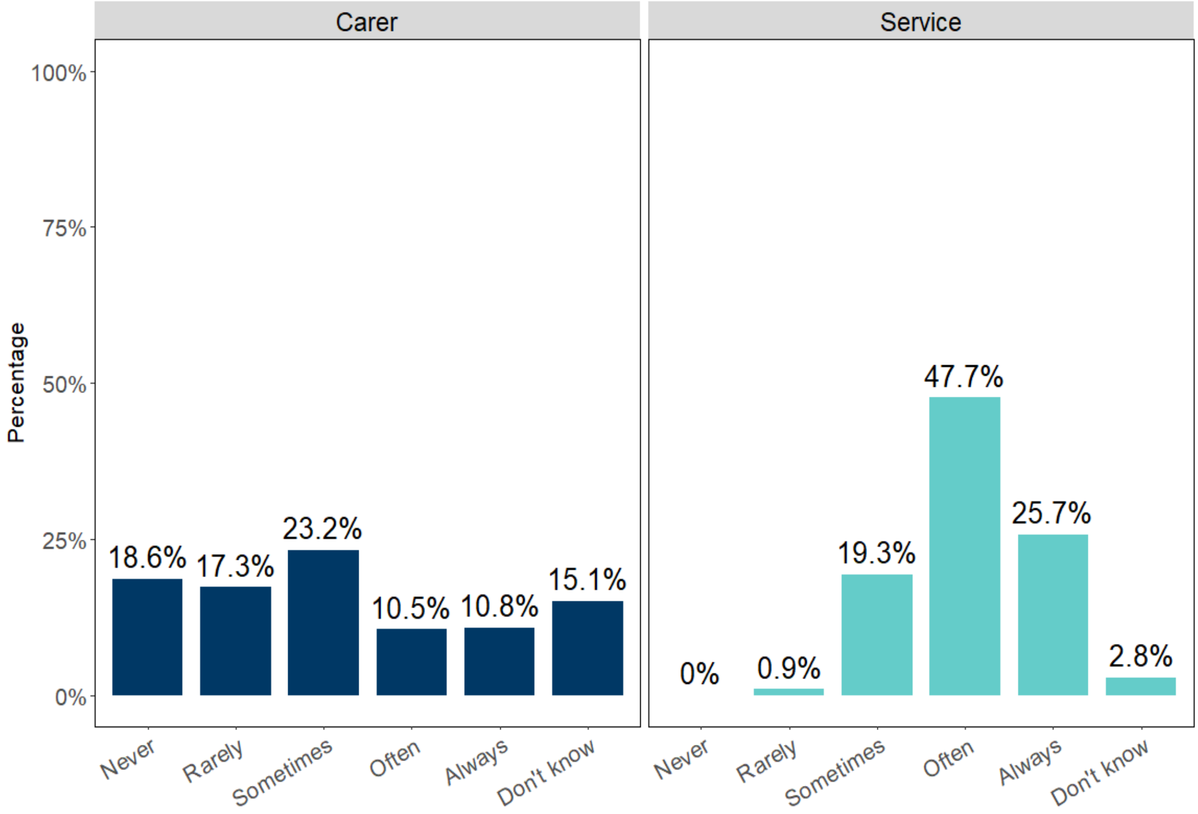
40 people (10.8%) told us that staff always provided support and a further 39 (10.5%) said that this often was provided. Slightly more carers (n=64, 17.3%) said staff rarely provided support, with the highest number of carers (n=69, 18.6%) telling us that staff never provided support to maintain the relationship they had with the person they cared for. Maintaining relationships is critically important for the carer and the person cared for and indeed the services who rely so heavily on this partnership. It is therefore very concerning to hear from carers that this is not being facilitated or valued.

One worker who supports young carers commented:

> *"Services in general have little awareness of young carers.*
> *They have no realisation of the trauma young carers go through*
> *and how being excluded increases this".*

We asked services the same question, the only result where there were similarities was with the view that both carers and services said that often support was provided; there were significant differences with the other scores and therefore very different perceptions of what is happening in practice.

Chart 8: comparing carers' & services' thoughts on help to maintain relationships



In both the carer questionnaires and in the Zoom sessions, we asked if there was anything else carers wanted to tell us about their experience of being involved, or not, in care and treatment.

Overall, people felt that being involved in care and treatment was difficult and they sometimes felt alone or invisible.

> *"Very haphazard .... there are far too many disparate organisations - some are charities, others are government / local authority."*

And:

> *"Not listened to, information is challenged and disregarded.*
> *Lack of empathy and kindness.*
> *Lack of respect."*

Similarly, we asked the services if there was anything else they wanted to tell us about involving families and carers. Of the 26 comments provided (24% of services opted to provide additional information) there were themes.

Services spoke about consent:

"Within drug and alcohol services often the person does not wish for their family to be involved and families struggle with the lack of information shared. It is difficult to make them aware that their relative has chosen for information to not be shared."

Some services spoke about how they involve families in certain aspects of care:

"Parents are often involved in assessments when a young person first comes into CAMHS. Input from that point on depends on the formulation (understanding of the problem and maintaining factors)".

There were services that said they involved carers in all aspects of care:

"Families are encouraged to be involved at all stages of the patient's care and treatment with the consent of the patient. It is recognised they have a very important role in the patient recovery."

There were additional challenges for young carers with reports that parents often tried to protect their children but this served only to increase anxiety. One young carer said:

"Can adults be honest as I can cope with things when I know. I worry more when adults keep things from me."

Key points

- It was a relatively small number of carers who responded saying that they had a family member or relative in hospital (20) or being cared for in the community (16). More than half of those with a family member in hospital said that they had been involved at the admission and review stage, but fewer reported being involved at the point of discharge. For those individuals in the community, carers were mostly involved with the formal review process.
- On this occasion, services who responded had a similar view in that they also thought that they nearly always or always involved carers.
- It was somewhat different when we asked carers about sharing or getting information and if services had helped to maintain their relationship with the family member/relative.
- We had a bigger response to this, with 235 carers telling us of their experience. More than a third of carers said that sharing information was either difficult or very difficult. Whilst services had a very different view, only 8 services said that they had difficulties getting information from carers.
- The differences in opinion between carers and services continued to be evident when we asked about how relationships with a carer were maintained. We heard a very mixed experience from the carers' perspective while three quarters of services told us that they often, or always, helped maintain the relationship.

Chapter 2: Getting information about a relative who is receiving health care and support

What we expect

Confidentiality around our personal information is a right we all have and something we all expect. The person receiving mental health care and treatment may or may not give their consent to sharing information with carers, relatives or other important people in their lives. Confidentiality is respected for all individuals in mental health and learning disability settings and we expect that, where consent to share is not given, it will only be breached by staff if there is a danger to the person or others.

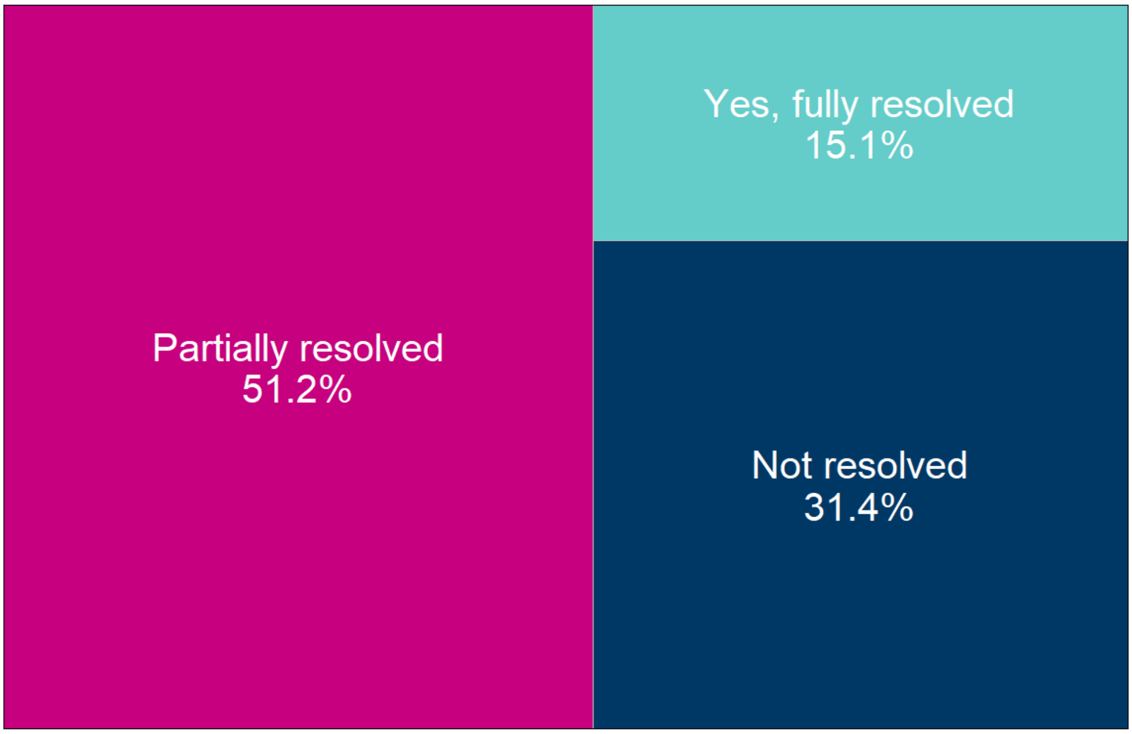
However, we expect staff to know that carers are a vital source of information and can help them learn about the person even if their patient has not given permission to share information. Staff may not be able to give specific information but they can still receive it.

What we found

We wanted to find out if carers had experienced difficulties in getting information about the person they care for and if they had, had the issue been resolved.

154 carers (41.5%) told us they had not had difficulty getting information about the person they care for, although slightly more carers (n=172, 46.4%) said they had faced difficulties. A few of the carers (n=39, 10.5%) didn't know if there had been any difficulties. For those carers who said there had been difficulties, more than half of the carers who responded (51.2%), said their difficulties were only partially resolved.

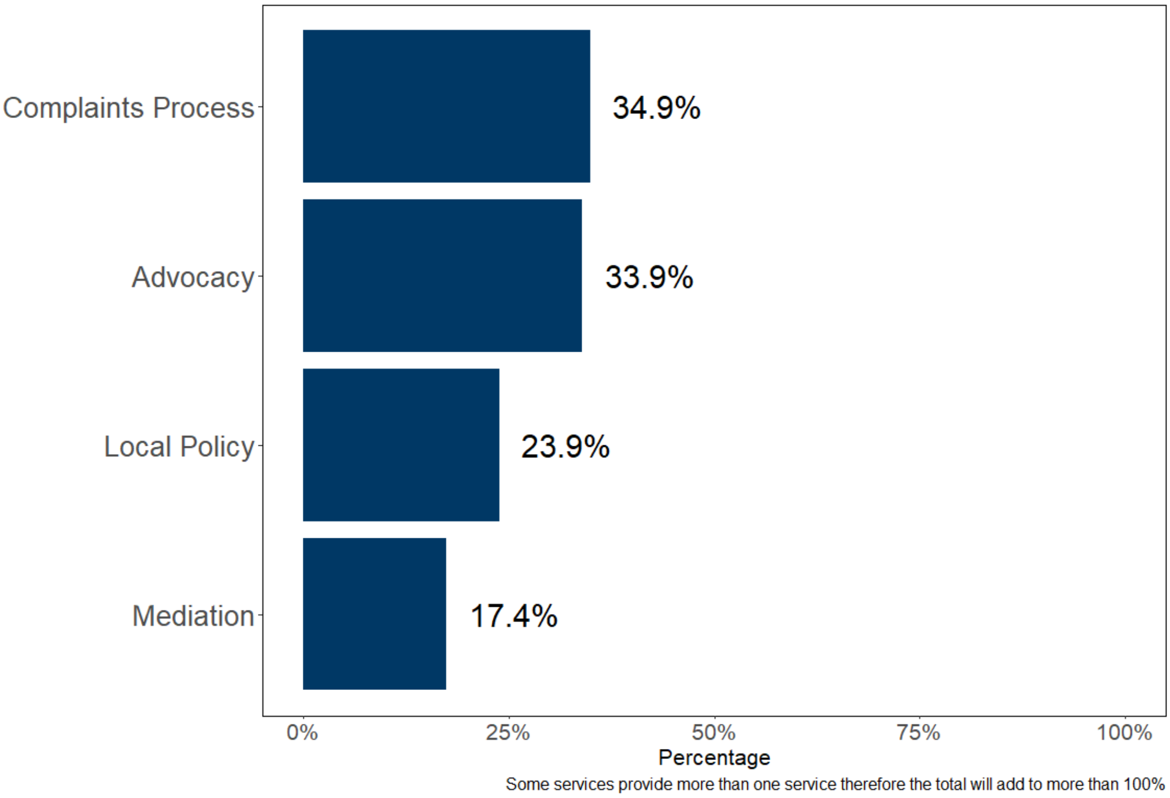
Figure 3: Resolution of difficulties



We wanted staff in the service to tell us if they had any difficulties giving information to families and carers, and if they did, what was put in place if this happens. The responses from the questionnaire indicated that more than half of the 109 services said that they had had difficulties (n=61, 56%,) with 45 (42.5%) indicating they had not.

For those services who had had difficulties, the following actions had been put in place when this happened.

Chart 9: Actions taken by the service when there are difficulties with information sharing



The most frequently used process was the complaints procedure, with 38 (34.9%) services using this approach when there were difficulties. At the same time, we heard from some carers that the complaints process was “exhausting” and “unsatisfactory”.

Some services said that there could be more than one option in place or used to try to address any difficulties or complaints.

Other answers that the services provided noted that it would be dependent on the patient’s wishes, that multidisciplinary team (MDT) reviews or discussions with the leadership team or with families had been put in place to resolve difficulties; we also heard that staff in services used clinical supervision for this purpose. Some services highlighted that they would access support for carers or refer to social services liaison.

How information is shared

We wanted to know how, and in what ways information was shared. We wanted to hear from carers if the person they cared for had ever refused for information to be shared with them.

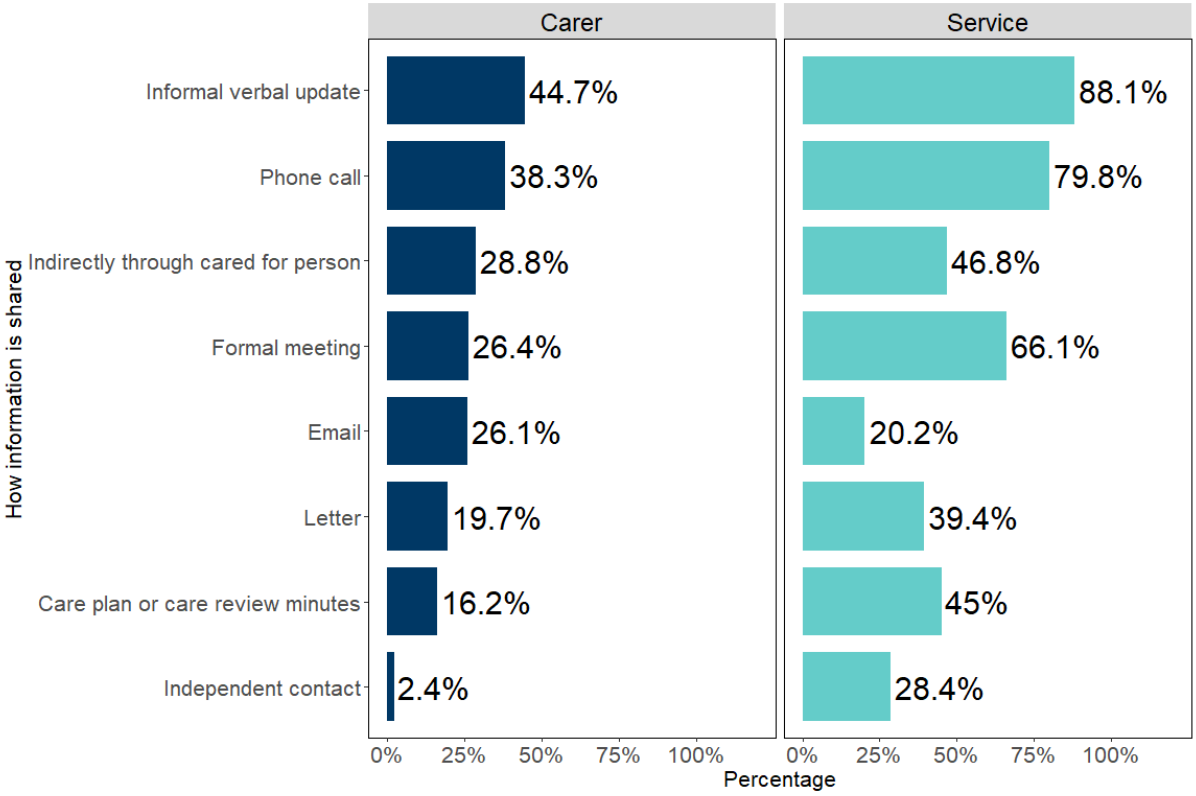
We asked staff to tell us how they shared information with a carer and what they did in the event that the individual under their care did not give consent for information to be shared with their carer. We asked services what action they would take when this happens.

When we asked about how information was shared with carers, people could choose multiple answers so the percentages in the chart will add up to more than 100%.

Many people still rely on informal verbal updates. When we looked at this more closely, 31 (8.4%) of respondents said that verbal updates were the only way they received information. 37 carers (10%) said they only received information about the person they care for indirectly through the person themselves.

Services agreed that it was mainly informal verbal updates that were used to share information (88.1%) although many services also said they provided information for carers in formal meetings, in the care plan and reviews, in letters and through independent contacts.

Chart 10: Comparison of how data is shared



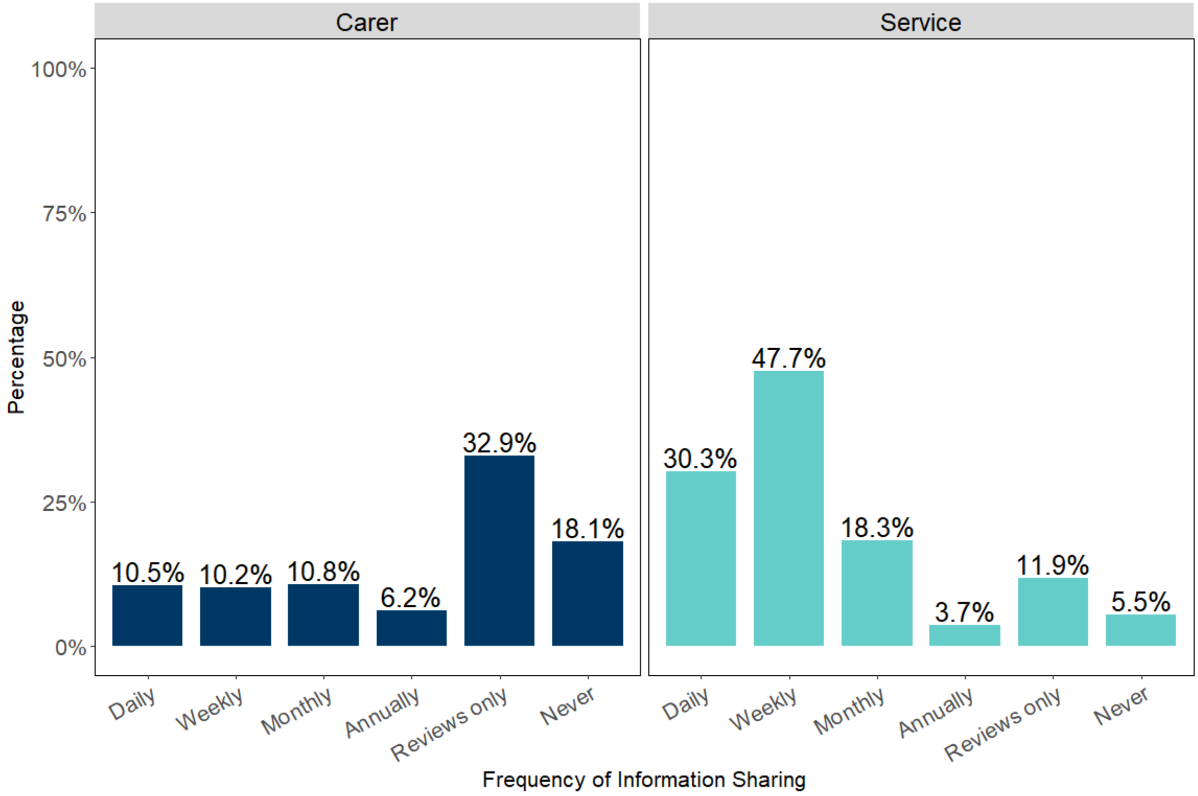
When information is shared

We asked about how often information was shared with the carer and again, people could give multiple answers. 67 carers (18.1%) said information was never shared with them. For nearly a third of carers who responded, (n=122, 32.9%) they said that information was only shared at reviews and for 101 carers (27.2%), this was the only time information was shared.

Another third of the carers who responded said that they received information on a daily, weekly or monthly basis (n=117, 31.5%,). Other answers that were given included comments from carers that information was shared on an ad hoc basis, or when needed. In some cases, this question was not applicable as no services were involved.

When we asked the services when they shared information with families and carers, there were clear differences with many saying that they involved families and carers on a daily, weekly or monthly basis; again, some services would have more than one option in place so percentages added up to more than 100%.

Chart 11: comparison of frequency of information sharing



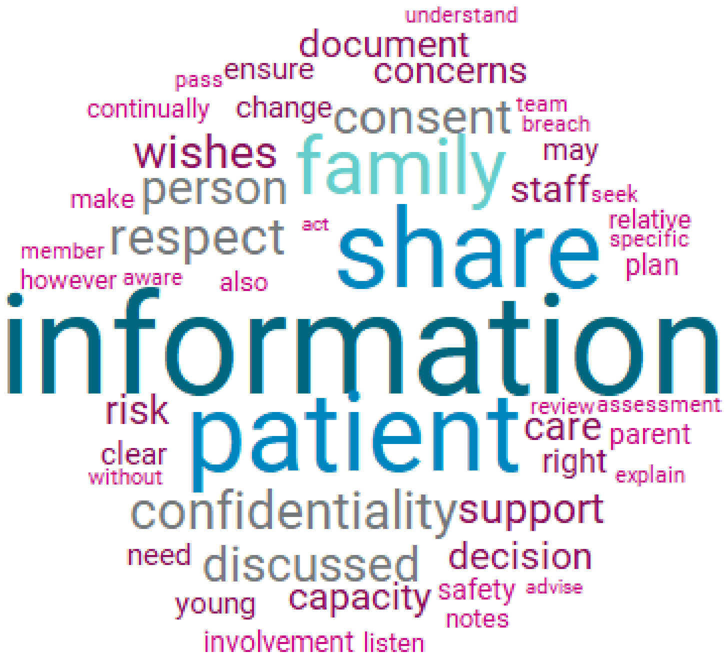
When permission to share information is refused

We asked carers if the person they cared for had ever refused permission to share information. Most respondents said no (n= 320, 86.3%), with only 38 carers (10.2%) stating that this had been the case for them.

When we asked services whether a person in their care had ever refused for information to be shared with families or carers, it was almost the opposite way round, with 80 services (73.4%) telling us that the person had refused for information to be shared and only 18 services (16.5) indicating that they had not had this situation. 6 service responses (5.5%) said this was not applicable in their service and we were missing information in 5 of the service questionnaires (4.6%).

Where services had said yes, they had had this situation, we asked what action the service had taken. Many services described practical solutions that included ongoing communication between families and carers and the patient, and constantly reviewing and revisiting the patient’s wishes, as well as signposting for carers and getting other agencies involved. Some services commented on capacity and risk and others mentioned policy or guidance.

Figure 4: word cloud of the actions that services take for sharing information



There were 89 comments that services provided with the actions they took when sharing information. There were several themes that came through with the first focusing on communication:

> *“We ask the young person what we can tell their family and encourage the family to communicate with their young person”*

> *“We give generic information to the family without breaching confidentiality. We apologise as this causes great concern to families, which is understandable.”*

There were comments about reviewing the decisions about sharing information:

> *“This is dynamic and they can and do change their minds which is fine.”*

> *"The care agreement is regularly looked at and discussed with the patient as they may change their mind as they progress and their mental health improves"*

Actions around signposting were noted:

> *"We might direct the parent/carer to other sources of support/information that might help them manage the difficulties that they are struggling with."*

With a significant number of services noting the need to record the decision:

> *"We have a 'consent to share' form which is handed out*
> *to all inpatients where their wishes can be documented,*
> *this will also be revisited should things change."*

> *"We add a warning to the system*
> *to ensure that no information is passed to them."*

Finally, for this section of the questionnaire, we asked carers for any other comments relating to their experience of getting information about the person they care for; we also gathered feedback from the Zoom sessions which gave us 36 comments from carers.

Figure 5: word cloud of carer experience of information sharing

Similar to the themes raised by staff in services, we heard carer views on communication:

> *"I am hugely disappointed about blocks in communication.*
> *There is no facility to text or message the community psychiatric nurse.*
> *No facility to email community mental health team or psychiatrist*
> *or to speak to the psychiatrist.*
> *The only possible contact for us is by phoning duty worker…"*

On their experience with staff and services:

> *"No transparency or consistency about using permissible communication,*
> *and very little attempt to help repair relationships when needed."*

There were a few positive comments about NHS and social work staff sharing information, or where the carer found the ward easy to deal with and for another, there had been pro-active contact with the psychiatrist involved with the person they cared for.

Carer responses mentioned that the capacity of the person they cared for came up frequently, with concerns raised that people either did not have capacity or that they were deemed to have capacity that the respondent did not always agree with.

In our second Zoom session, one carer told us:

> *"Can I just add that my husband's got dementia,*
> *I've got power of attorney, so obviously I'm included in everything*
> *and every multidisciplinary team meeting I'm present there,*
> *but all I can say is although I'm at the table, you're fighting all the time.*
> *But just to give a different perspective, I am at the table,*
> *I have power of attorney, I'm involved in everything,*
> *but there's still a lot of barriers"*

Key points

- This chapter provides more detail about the difficulties for carers and services when information needs to be gathered or shared. Nearly 50% of carers (172) told us that they had difficulties with this, and more than half of the 172 said that these had not been fully resolved.
- Services who responded also said that they had difficulties with getting/sharing information (60%). However, while services told us that they had a number of ways to resolve difficulties, the complaints process was used in more than a third of occasions; we heard from carers that this process was "exhausting".
- Another issue that came to light was the way in which some carers got information. The services themselves told us that they mostly (88%) used informal, verbal updates as the way to communicate with carers about their family member, or person that they cared for, whilst for 10% of the carers, hearing it from 'the patient' was the route that was used for them to get

information. Only a quarter of carers (26%) said that the formal review meeting was how they were updated, but nearly two thirds of services (66%) said this route was used.

- There was a significant difference in how often carers thought they were updated, as opposed to the service’s view of the frequency of information sharing. Only a third of carers said that this was done on a daily, weekly or monthly basis compared to the services’ view that updates to carers were provided this frequently most of the time (90%).
- There was one other point to note in relation to getting and sharing information. A small group of carers (10%) told us that the person they cared for chose not to give permission to services to have their information shared, whilst 73% of services said this was an issue.

Chapter 3: Responsibilities of staff/services to engage with and support carers and families

What we expect

We expect that carers and family members are considered as unique individuals with their own fears, hopes, concerns, home circumstances and expectations of themselves as carers. We know that some carers do not define themselves as such, they see their role as their duty and do not expect any support for themselves. Other carers are more aware of their rights and informed by organisations and feel able to challenge where these rights are not respected. All carers however explain that they want their relative to get the best care and support and we expect services to engage with them to achieve the best outcomes possible.

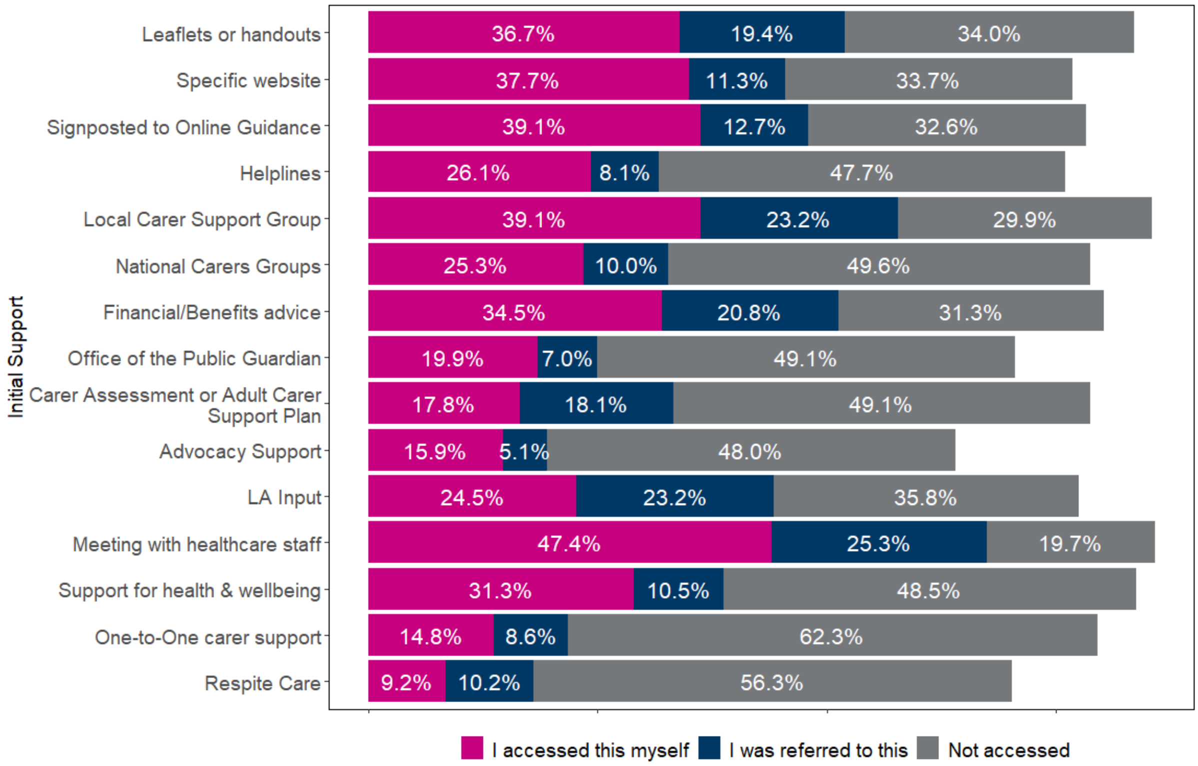
Our expectation is that mental health and learning disability services staff are informed by the Triangle of Care guide which was launched in July 2010 and has gone on to be developed as a self-assessment tool. This approach encourages partnership working with carers at all levels of care from the individual to overall service planning in line with carers' rights under the Carers (Scotland) Act. The outcome should be support to maximise and sustain the contribution of carers as key players in support and recovery of the person they care for.

What we found

We asked carers what support they received when they first started to look after the person they cared for.

We gave respondents a broad range of supports to select from; they were able to select more than one. Chart 12 below notes what carers accessed themselves, what they were referred to and what they did not access.

Chart 12: what support did carers receive at the start



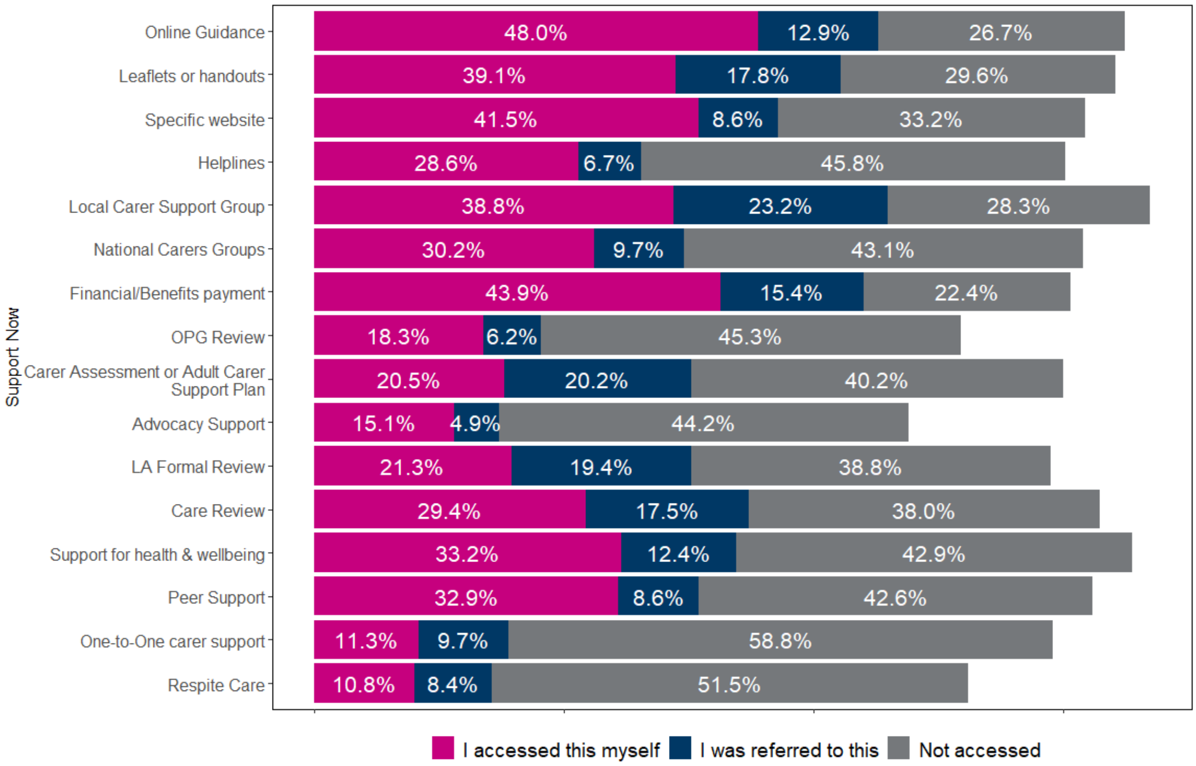
Missing and Not Applicable answers have been removed. Young Carers Statement also removed to maintain confidentiality.

We heard from 50 people (13.5%) that they had received no initial support at all. More than 60% had not been able to access any one-to-one carer support and nearly 80% had not accessed either a local or national carer support group. Nearly 50% told us that they had not had an adult carer support plan or young carer statement. These plans and statements should include an emergency care plan if the carer becomes unwell. 131 people however told us they did not think an emergency plan was required in their circumstances. 77 (20.8%) people told us they had access to out of hours services and crisis management support was available for a further 23 people (6.2%).

> *"As a young carer I have never been offered a carers assessment or any support. It feels like because I am young and have grown up around care that I am fit enough to cope mentally and physically."*

Given that for most that responded, they had been unpaid carers for a period of more than a year, up to 20 years or more (n=356, 96%), we wanted to ask about the support that carers receive currently.

Chart 13: what support carers currently receive



Missing and Not Applicable answers have been removed. Young Carers Statement also removed to maintain confidentiality.

Some support that carers accessed themselves remains consistently available, such as leaflets and handouts, specific websites and helplines for carers. Others, continued not to be available including one-to-one support and respite care.

What was notable from the support received initially, and then again with what carers said they were currently receiving, was that carers are still doing the majority of work themselves to access the supports they need or have not had access to them at all.

Of the 30 comments we received from carers describing their experience, generally most were critical of having an adult carer's support plan with one person commenting:

> *"I've found the carers assessment a complete waste of time tbh!*
> *It's not given me any further support (even though it highlights*
> *that I should be receiving further support!)"*

and about the experience of services:

> *"It is a constant struggle.*
> *I always feel like I am battling against services to get even a little support*
> *or even acknowledgement of what I do each day."*

Where there were positive comments, they related to local carer centres or charities that carers could access:

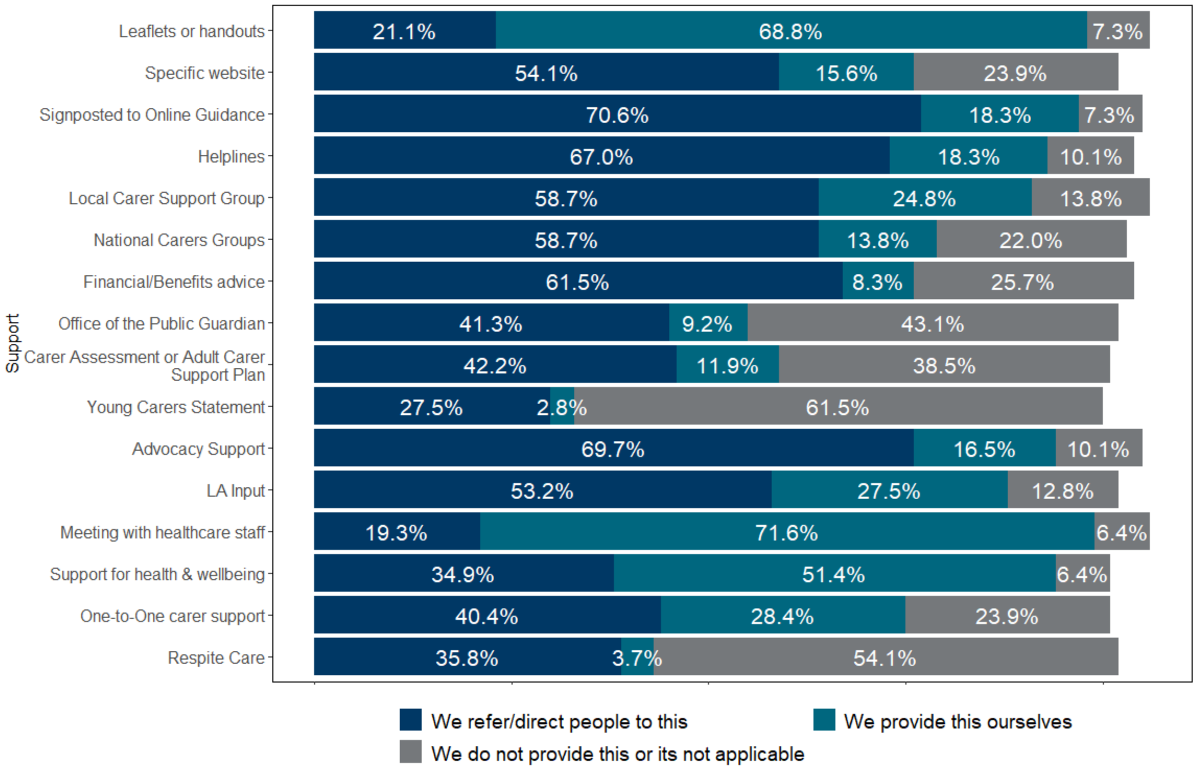
> *"The centre is amazing - they have done everything for me*
> *and I don't think I'd even be alive now if it wasn't for them."*

What the services reported to be providing for carers

We asked services what support they directed carers to, or provided for carers, based on the same list of supports that we had asked carers about.

There were 109 responses from services, but this does not represent all health boards; there were areas that did not respond to the questionnaire. Chart 14 below sets out the support that services direct carers to or provide themselves.

Chart 14: what services provide for carers



From the information provided, the supports that services told us that they mostly refer or direct people to were websites, online guidance and helplines. In terms of what the services provided themselves, they stated the support was in the form of leaflets and handouts (n=75, 68.8%). We heard from one carer during our Zoom sessions that there was:

> *“Too much signposting online and no one taking a lead to coordinate and help people practically until crisis.”*

The majority of services also recorded that they offered meetings with healthcare staff (n=78, 71.6%) and more than half also said they provide support for health & wellbeing (n=56, 51.4%). However, this seems to be in contrast to the carers’ findings where far smaller percentages of people said they were referred to this type of support both initially and currently. We heard from a carer in our final Zoom session:

> *“At the moment there is no support as a carer.*
> *There’s a whole world of theoretical things,*
> *this is what should happen and the rest of it,*
> *but in reality there is very little”.*

We asked services if they used Triangle of Care guidance, and if they did, how was it used by the respondent.

25 (22.9%) services said they did, 50 (45.9%) said they did not, while 33 (30.3%) said they did not know whether this was used. For the services that were using the guidance, there were some broad themes about the impact of the Triangle of Care:

> *"We work as the professional side alongside the carer and patient and this is a continuous loop where all parties work together, gather information, share and learning from each other".*

Once again there were different reports between carers and services on the level of support provided. There can be no dubiety however that where mental health and wellbeing supports are not in place for carers, there is a risk of creating further demand on mental health services. 89.4% of those carers who engaged with us reported on how fragile their own mental health is as a direct result of their caring role (Chart 4).

Key points

- An intention of the Carers (Scotland) Act 2016 was to better support carers to continue to care, if they wished to do so, whilst also allowing them to have their own life.
- Almost 60% of the carers we engaged with said there was a lack of access to one-to-one support whilst 60% of services said they made an onward referral or provided one -to-one support directly. Only a third of carers (33%) said that they had received support for their own health and wellbeing, yet 85% of the services we heard from said they either referred on or provided this.
- What was consistent was the lack of carer support plans/young carer statements where 40% of carers said they had not had this. The same percentage of services told us they do not offer this. Whilst the responsibility for plans and statements lie with local authorities and locally funded carer organisations, we would expect health services to make appropriate referrals.
- Without access to all of the possible resources that could offer better support to carers, the struggle they described to us, along with their ongoing concerns about the potential for crisis, is unlikely to maximise and sustain their contribution.
  The experience shared with us below captures this battle:

"My mental health was starting to decline… I kept fighting and fighting, but I thought I need to go to the doctor's because I need to go back on antidepressants. But I didn't. I managed, you know, just to use techniques to keep myself well, because I've worked in mental health, so I kept at it.

I'm one of the fortunate ones that practises techniques all the time. But I can assure you, my mum's impacted me quite a lot - my personal life, my relationships, my grandchildren, even having a relationship with my grandchildren was difficult because it was constantly, I can't have the grandchildren this weekend because I've got to look after mum.

So that impacted, until I managed to put my hands up and say look I'm done, I'm done. I need a care package in here and you know even then my mum was like "you're abandoning me I can't believe you're abandoning me" and then I thought no, I'm not abandoning you mum, I'll still be here.

*Anyway, I managed, I was fortunate I managed to get a care package in for mum four times a day so you'll know four times a day three hours a day is a massive care package and you'll know how ill my mum is because it's a massive care package. I just had it, it was impacting my life, providing care for my mum. It's like role reversal. I became the mum; she became the child***".**

- The experience reported above not only gives some insight into the turmoil faced by carers, but it also shows the level of expectations are not high when a daily three-hour care package is described as 'massive'. The fact that this carer regards herself as 'fortunate' because her responsibility has reduced from 24 hours per day to 21 hours is shocking to most.

Chapter 4: Transitions

What we expected to find

The transition between services is an important aspect of the delivery of mental health services. We would expect that the services with the greatest expertise in relation to the care needs of an individual are involved in providing the mental health care for them.

Action 21 of Scotland's mental health strategy 2017-2027 responded to the need for improved transitions between child and adolescent mental health services (CAMHS) and adult mental health services. Whether the move is from CAMHS to adult services, or from adult to older adult services, or a move within a service to a more specialist team, we would expect to hear about preparation, planning and effective communication to ensure that individuals, their families and carers feel supported and informed, thereby reducing the concerns and anxieties that can occur at this time.

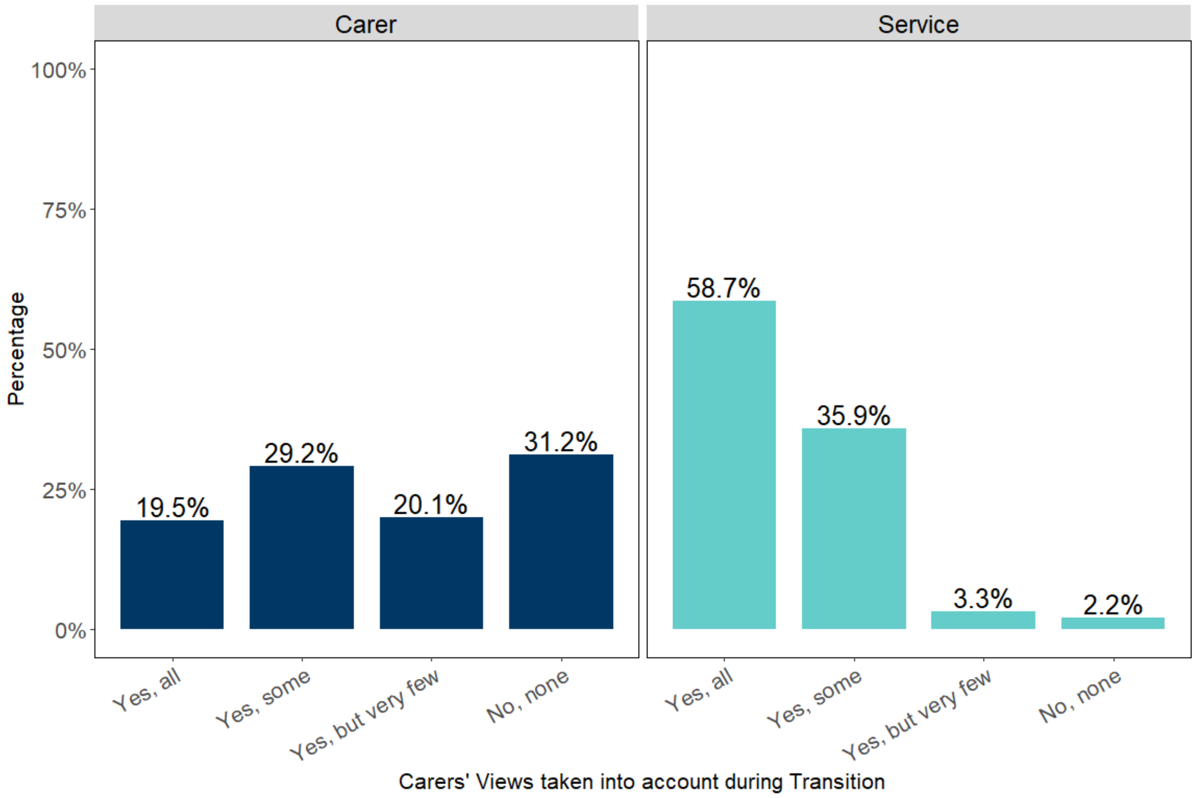
What we found

We asked carers about their experience of transitions that may have taken place with the person they care for. We wanted to know about the transition care planning that took place and to hear about anything else they wanted to make us aware of in relation to this.

154 carers (41.5%) said that the person they care for had transitioned or transferred between or to another service; 165 (45.5%) said that the person they cared for had not gone through a transition, 44 (11.9%) did not know and 8 (2.2%) answers were missing.

Where people had answered yes, they were asked about whether their views were taken into account. 30 out of 154 carers (19.5%) said all their views were taken into account, 45 (29.2%) said that some were taken into account, 31 (20.1%) said very few of their views were taken into account and the largest group of respondents (48, 31.2%) said none of their views were taken into account during the transition or transfer.

Figure 6: carers' views of transition, and services' views of carers' involvement at transition



We had further detail, with 30 comments from carers about their experience of transitions, most were received about the young person to adult service transition.

"We're just seen as interfering parents
who they'd much rather weren't involved at all."

And from our final Zoom session one parent shared their experience which is likely to be representative of others.

"Once she left school you drop off a cliff,
I mean everybody who's got an older child knows
that this transition period is like entering a black hole
when they're 16 to 18.
You enter a black hole where you're neither a child nor an adult.
And so nobody knows what to do with you.
You go off into outer space, and then you come back again at 18."

In our questionnaire to services, we asked if they take views of families and carers into account when a transition takes place, e.g. between services.

Where services had experience of this, their answers were different to carers' experience. 54 services (58.7%) said they took all carer and family views into account, 33 (35.9%) said that some carer and family views were taken into account, only 3 (3.3%) said a few of carer and family views were taken into account and 2 services (2.2%) said no views were taken into account during the transition.

Key points

- Of the carers who had been through the transition from one service to another with their relative, we heard that for over 50% (79) very few or none of their views were taken into account.
- However, the response from services indicated the opposite view; more than 90% of services which replied to this question said that they either considered all or some of the views of carers and family members.
- Concerningly, there was more negative feedback from carers and parents of young people about transitions from child and adolescent mental health services to adult mental health services.

Conclusion

The Mental Welfare Commission for Scotland has a strong alliance with the carers who come into contact with us through our core functions of visits, monitoring of the Acts (the Mental Health (Care and Treatment) (Scotland) Act 2003, Adults with Incapacity (Scotland) Act 2000), investigations, advice and information giving, influencing and challenging.

Undertaking this themed piece of work has helped us to hear more clearly the voices of carers as a collective.

We acknowledge that throughout this report there is a disconnect between the experiences of the 371 carers who responded to us and those who responded on behalf of health boards. The experience of the carer respondents differed to the generally positive contribution reported by the 109 services. (It is important to note that the services which engaged with us as part of this work are not necessarily the services the carers who responded to us had experience of). The fact is however that we do not know why there is such a disconnect and our only comment is that this work has highlighted these different perceptions and any gaps need to be bridged.

A consistent theme we heard was the battle for carers to be actively included and respected as partners in care for their relative. This is not a resource issue but an education and culture issue that requires to be understood and addressed. There is work progressing. NHS Education for Scotland is developing learning resources that will enable health and social care staff to identify, support and work with carers as equal partners in care (EPiC). For those carers who engaged in this themed work, this cannot happen quickly enough. There is an urgent need for awareness raising, education and clarity of expectation upon health, social work and social care services about their responsibilities towards carers.

We heard that carers are so focussed on their relatives, sometimes at the expense of their own rights; including the right to respect for private and family life, home and correspondence (Article 8) and the right to be free from discrimination protected by both the Human Rights Act (Article 14) and Equality Act 2010[1]. The Commission and services need to promote the rights of carers so that these are known and can be realised.

There is also genuine hope that the new legislation, the Care Reform (Scotland) Act 2025, has finally listened to carers and committed to unpaid carers having a specific legal right to sufficient breaks and local authorities having a new duty to promote the take up of financial and other support by carers too.

However, the more than 90 recommendations made to support carers referred to at the start of this report which have yet to be fully delivered upon; the aspirational Carers (Scotland) Act 2016 which had no resource to match, cautioned against too much expectation. The British Association of Social Workers explain:

> *"Legislation that increases expectations without assurance of resource to meet those expectations risks destroying trust between communities and services when they are unable to deliver. In our opinion, the majority of the Care Reform*

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[1] These are detailed in the BIHR Pocket Guide for Carers.

> *Bill and its proposed amendments may have little effect on the delivery of services, which are, on the whole, suffering from a shortage of resource rather than any lack of purpose, direction or ethics".*

Recommendation

At the start this report we asked whether Scotland is now the "place where all carers are recognised and valued for the contribution they make, where they are enabled to provide the right support for the people they care for while living full, rounded lives"? (Kevin Stewart, Minister for Mental Wellbeing and Social Care). We have clearly heard that Scotland is not that place. This is simply not good enough.

Despite the multiple recommendations made to date to support carers and even with some work progressing to action these, there remains little improvement in the experience of those carers who engaged with us.

We do not want to clutter the recommendation landscape further by duplicating what has already been suggested however, to ensure pace and commitment we make one recommendation to Scottish Government in response to the work we have undertaken.

Our single recommendation for Scottish Government is:

- **to ensure that the Care Reform (Scotland) Act 2025 makes explicit reference to carers being recognised as equal partners in care.**

Equal partners in care means explicit recognition of carers as genuine partners in care with rights to give and receive information, to be included at every stage of care planning, discharge planning and transition points across mental health and learning disability services. And for services to undertake audits to evidence this implementation in practice.

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npm
national
preventive
mechanism

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