

Angus Carers Strategy 2023-2026
Statement of Engagement

Introduction

The voice of lived experience has been at the centre of the development of the Angus Carers Strategy 2023 – 2026. This report provides details of the engagement activities carried out with Carers and health and social care professionals across Angus to develop the Angus Carers Strategy 2023-2026. This includes:

- Review of the progress of Carers in Partnership: A Strategy for unpaid Carers in Angus 2019-2022
- Critique of current processes and provision for Carers in Angus.
- Feedback on the draft Carers Strategy Summary 2023-2026 and Plan On A Page

We will use this information to guide our next steps for improvement.

Carer Engagement

Methodology

Engagement took place over 6 weeks commencing on 25th October 2022 and sought to understand the experience of Carers in Angus in order to understand carers' experience of current service provision. A number of methods were used to engage with stakeholders, these included:

- Survey available online (hosted on Angus Health and Social Care Partnership website and shared via social media), paper copy (available in large print and different languages in request) and easy read.
 - Survey was shared with a wide range of organisations across Angus who were asked to share with their respective networks.
 - Posters were also prepared and displayed in local Health Centres, Leisure Centres, Museums and mobile libraries.
- Face to Face and online discussions via attendance at Carer social events across Angus localities: using the 'Carer Cuppy' events enabled a relaxed atmosphere and detailed insight into the lived experience of carers in Angus.
- Online discussions.

The online survey was more extensive and asked more questions about how supported Carers feel in their caring role. The face to face discussions at Carer social events were deliberately more concise and open ended in their questioning.

Carers in Angus were asked about:

- The Angus Health and Social Care Partnership (AHSCP) vision for Carers
- The main barriers experienced in a caring role
- The supports that help Carers most
- Experiences of caring in Angus

Angus Carers Centre delivered workshops with young Carers to empower them to influence future practice and ensure they are supported, listened to and valued. Methodology facilitated both quantitative and qualitative data.

Results

Over 140 Carers in Angus shared their views. Respondents spanned a range of ages but the majority were over 65 years of age and caring for a spouse.

Although some positive experiences were shared, the majority of feedback highlighted how challenging a caring role can be.

Figure 1. Examples of some of the challenges experienced by Carers

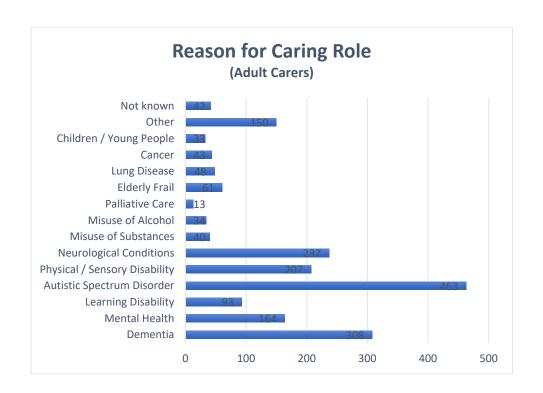


Figure 2. Examples of how rewarding a caring role can be.



Reason for caring role

Carers in Angus are supporting people for a variety of reasons, as shown below:



Identifying as a Carer

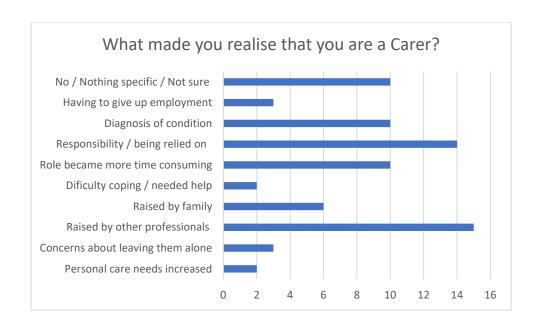
We asked Carers in Angus if there was anything specific that made them aware of their caring role. For some a diagnosis validated their role, for others the onset of concern triggered their recognition:

"When I started worrying about leaving him alone."

For many even a professional highlighting their role led them to question:

"My husband was in hospital for a long time and the staff kept referring to me as his carer although I said, No I'm his wife, your vows say in sickness and in health."

Responses highlight that in general, people only start to realise they are a Carer when they experience significant difficulty. This highlights the importance of promoting the Carer role and forming relationships with Carers as soon as possible.

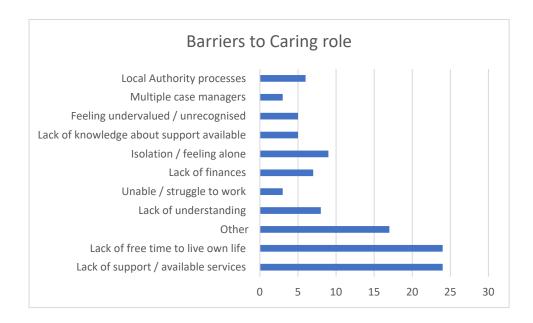


Barriers to Caring

Carers considered that there was a lack of available respite as a barrier to their caring role. Some people told us that they found it difficult to attend support groups designed to help them, attend their own medical appointments or find time to have enough sleep. Others highlight difficulties finding time to spend with other immediate family members and the complications of juggling multiple responsibilities.

"I want to live my own life but it's hard."

"People just don't get that you almost have two lives. One, where you cherish what you've got and the other one, the niggling worry in your head about the person you care for."



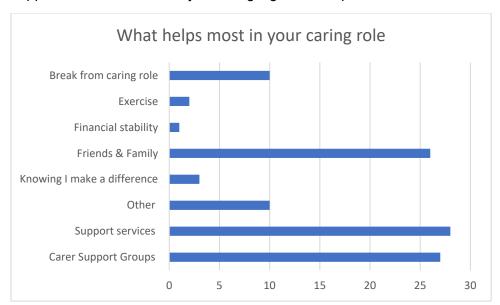
Carers told us that a frequent lack of understanding amongst the general public about a range of long-term conditions caused concern. Other comments relate to a perceived lack of

targeted services for conditions such as Parkinson's disease, challenges with Blue Badge renewal and inconsistency amongst professionals in referring Carers to support services. Another common issue raised was a difficulty with sourcing information regarding supports available for carers and the people they support.

Young Carers highlighted the dichotomy of being responsible enough to undertake a caring role but not involved in decisions or trusted to collect medications. Struggling with school was also a frequent response as was lack of time to socialise with friends or spend doing family activities if their parents are busy caring for a sibling.

Valued Supports

Carer support groups and services were highly valued in Carer feedback, as well as the support of friends and family. This highlights the importance of services in carers lives.



"I receive counselling from Angus Carers Centre and opening up about how I really feel is good."

"Carer Cuppy groups really help....speaking to other carers who understand."

"Working alongside my son's mental health team and seeing him content."

"Brilliant to be with people who understand at the Kirrie Carer Cuppy."

"The Carers meeting – I can be completely open and honest about my circumstances. I tell them things I can't tell my own family."

"The carers from the agency are really good. I'm exhausted after every weekend (when they don't attend) and couldn't manage without them."

Young Carers

We asked young Carers if there was anything specific that made them realise that they are 'Carers' and it became apparent that they are much less likely to make this connection alone:

"School talk on being a young Carer."

"I didn't realise that I was a Carer until I met my worker."

"Being different from my friends."

"School stressing me to tell them what was wrong with my parents."

Schools were praised about the way they supported young Carers to identify as Carers but were also named as a barrier. When asked what would make the greatest difference to their lives one particular comment summarises several responses:

"If schools knew more about what they (young Carers) are."

This shows the importance of working in partnership with schools to support staff, not only to identify young Carers and refer them to the appropriate supports, but to recognise the additional challenges that young Carers experience. Many young Carers reported struggling with school life due to their additional responsibilities.

Parent Carers

Multiple responses from parent Carers of children with additional support needs highlighted a lack of understanding from the public as a barrier;

"Other people's opinions and behaviour."

"Relating to other parents and adults – feeling isolated."

Time to spend with other family members was also consistently reported as difficult to find and a source of anxiety:

"Finding it hard to work or get any couple time with my husband."

"Giving everyone enough of your time – partner, family and person you care for."

They re-iterated the comments of other Carers in asking for clarity of information on supports available:

"More information on schooling, childcare, respite options for children with additional support needs."

Carers of people with mental health concerns

Carers spoke of feeling isolated and stigmatised by public perceptions about the people they support:

"Our normal not being normal to others."

Our Vision

We asked Carers to provide feedback about our Vision:

Carers of all ages are valued as equal partners, fully involved in shaping services and supported to have fulfilling lives alongside caring.

The vision was well received however many questioned its' deliverability.

"The vision is relevant but may be difficult to implement due to budget restrictions."

"The vision is really good but sadly I don't think it will happen in practice."

"We will have to continue to battle to get it."

Thematic Analysis

When all answers were collectively considered four themes emerged:

Communication

Carers told us about difficulty with finding information to support them in their caring role; found difficulty contacting case managers; felt frustration with the process for agreeing support; felt frustration with the terminology used when discussing the impact of their caring roles. Carers also spoke about challenges with having their care needs understood.

Continuity of Care

Multiple comment were received which highlighted challenges when there is a lack of continuity with Care Managers which led to Carers feeling frustrated when they had to repeat their circumstances.

Clarity

Several responses detailed confusion around the types of supports available and called for more information especially in relation to services that are chargeable and how a Carer budget can be utilised.

Capacity

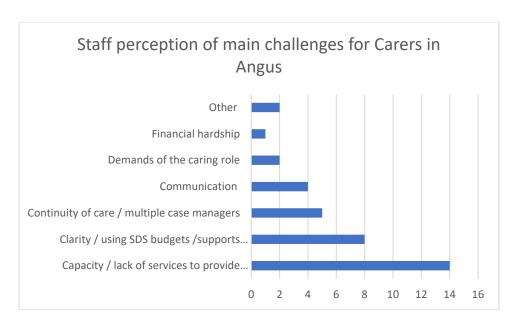
Carers in Angus spoke of their frustration with accessing 'replacement care' from care providers due to limited capacity and long waiting lists.

Staff Engagement

Methodology

A targeted qualitative staff survey was completed by 23 professionals across AHSCP who represented a range of frontline services, for example home care assessors, community nurses, social care officers, service leaders and care managers. Staff were asked for their opinion about the main challenges facing Carers in Angus. We also asked staff to describe their experiences of working with Carers to meet their needs.

Similar to the feedback received from Carers, the themes to emerge were linked to capacity, communication, continuity of care and clarity.



Staff highlighted similar themes in relation to meeting the needs of Carers.



Communication

Staff recognise the challenges that Carers may experience when trying to make contact with services and the negative impact this has on their relationship with them. They also report time consuming difficulties liaising with other professionals when working collaboratively. Volume of paperwork is stated as an additional challenge by staff.

Continuity Of Care

Staff turnover and large caseloads prevent staff from maintaining therapeutic relationships with families and the impact that this has on Carers is appreciated by staff.

A 'reactive' culture is reported as the requirement to prioritise urgent cases dominates their decisions. Other difficulties reported centred around the geography of Angus and availability of services for those residing in rural locations.

Clarity

Carers rights and entitlements have been developed via many legislative acts and updates, and several staff reported that the knowledge base required to achieve excellence for Carers is challenging. Use of SDS budgets is deliberately flexible to accommodate individual needs and personalise supports, however such varied possibilities are highlighted as challenging.

Capacity

Staff reported concerns that a lack of care capacity results in Carers having to continue to deliver sometimes challenging levels of care.

Staff share the frustration of Carers with difficulties experienced sourcing respite care.

Their own capacity and workload is also highlighted which can impact of their ability to support people in a timely manner.

Managers spoke about a lack of training available for staff about Self Directed Support.

Staff also described challenges with support people to realise their caring role and accept support. They also described challenges with differences of opinion between Carers and their supported person regarding the level of support the Carers requires.

Our response to what people said

Engaging with Carers and staff early in the process to produce the Angus Carers Strategy and has enabled us to use feedback to shape our priorities for the next three years:

- 1. Visibility: Carers will be more visible
- 2. **Empowerment**: Carers will be supported and empowered to take full control their caring role
- 3. Life-balance: Carers will have a life outside of caring
- 4. **Influencing**: Carers will be fully involved in the planning and shaping of services
- 5. **Equity**: Carers will be free from disadvantage and discrimination due to their caring role

Draft Angus Carers Strategy 2023-2026

Methodology

A number of methods were used to engage with stakeholders to gain feedback on the draft Angus Carers Strategy. The engagement survey took place over four weeks commencing on 4th May 2023 and included:

- Survey available online (hosted on Angus Health and Social Care Partnership website and shared via social media, paper copy (available in large print and different languages in request) and easy read.
 - Survey was shared with a wide range of organisations across Angus who were asked to share with their respective networks.
 - Posters were also prepared and displayed in local Health Centres, Leisure Centres, Museums and mobile libraries.
- Attendance at Locality Improvement Groups
- Distribution to Team leaders in AHSCP for comment

Results

Responses were received from 120 stakeholders including Carers and professionals.

Feedback was mostly positive. The intention to support Carers to recognise their caring roles was well received as were actions to increase the diversity of registered Carers.

Stakeholders recognised the need to explore issues experienced by Carers who live in rural areas of Angus.

Scepticism around achieving the vision was expressed by some Carers who felt that lack of care capacity to facilitate Carers respite will hinder success:

"Sadly, if a carer can't get the help required then these are just words and are totally meaningless. If there aren't any professional carers, then an unpaid carer has no normal life."

Other comments highlighted that all information needs to be available in multiple formats.

Our response to what people said

We have listened to and read the feedback from people who use or deliver Carer support services in Angus and amended the content of the ACS 23-26. For example, we have:

- Changed the reference from child Carer to 'young Carers'.
- Included a reference to parent Carers of adults with learning disabilities when addressing 'transitions.'
- Addressed staff training needs within the improvement actions of the delivery plan.
- Acknowledged workforce challenges which impact on our ability to increase care capacity but we will continue to explore all options.
- Redesigned young carers services into three bracketed age groups to better meet their different needs.

Angus Health & Social Care Partnership will continue the conversation with people of Angus as we deliver the ambitions of the ACS 23-26.