



south ayrshire
health & social care
partnership

Carers Engagement Day

Summary Report



April 2018



Background

South Ayrshire Health and Social Care Partnership is committed to developing an Adult Carers Strategy and separate Young Carers Strategy as part of the implementation of the Carers (Scotland) Act 2016. These strategies must contain, amongst other things, plans for identifying carers, carer pathways and plans for helping relevant carers put arrangements in place for the provision of care in emergencies.

To help shape early thinking around the key themes and priorities for both strategies, a Carers Engagement Day event was held on Friday 16th March 2018 at County Hall, County Buildings.

The event was attended by over 80 stakeholders, including carers, carers' organisations, third sector and advice and advocacy groups.

Attendees were split into facilitated tables of 10 to stimulate debate and discussion around three open key questions:

- What does caring mean to you?
- What would good support for carers look like?
- What are the best ways to provide information and advice for carers?

We would like to thank everyone that took part and contributed their views during the Carers Engagement Day.

The following summary report provides a high level summary of the main themes and ideas which emerged from the Carers Engagement Day. The feedback gathered will inform the creation of a draft Adult Carers and separate Young Carers Strategy, which will be issued for public consultation in August 2018.

The summary report is structured by themes as follows:

Section 1:

Theme - What Does Caring Mean to You?

Section 2:

Theme - What Would Good Support for Carers Look Like?

Section 3:

Theme - What Are the Best Ways to Provide Information and Advice for Carers?

Section 4:

Conclusion and Next Steps

Some individual responses below:

“All caring roles are very different”
“Being able to enjoy normal life”
“Builds up gradually, what you take on at the beginning is not what you end up doing”
“Can define your life”
“Cannot always rely on family/friends”
“Carers are not always old people”
“Carers’ rights?”
“Guilt for leaving the person I care for to get a break”
“Harder fighting the correct standard of care than the actual disease”
“Having to get on with it”
“Helping people to continue to live in their own homes”
“I didn’t think of myself as a carer”
“I do everything for them”
“I don’t really look upon myself as a carer, just a wife looking after her husband to the best of her ability”
“I was just being a caring mum”
“I’m not a nurse, but I am a nurse”
“If everything that is on paper actually happens it would be great – practice what they preach”
“Impact of caring - a burden can become a mental health issue”
“Impact on my health after the death of person I cared for”
“24/7 - Impacts on free time”
“Impacts on my education”
“Isolating”
“It can be stressful having to stay up late and no sleep”
“It’s important”
“It’s not just a physical care, emotional care is involved also”
“Keeps my family together”
“Labour of love”
“Liaising with lots of different agencies”

“Communication is difficult, hearing problems, speech – frustration”
“Don’t know if we are doing it the right way”
“Encouraging the person I care for”
“Extra responsibilities/work load”
“Feel that it is - my duty”
“Fighting all the time - battles”
“Financial worries”
“Looking after family members but roles can change”
“Loving someone unconditionally and doing things for them no matter what”
“My sanity”
“No family/friends to care for me”
“Nobody has ever asked until last week what does that mean to me”
“Not looking after yourself”
“Often those being cared for do not realise that they are causing difficulty”
“Own life on hold”
“Put upon”
“Right hand doesn’t know what the left hand is doing”
“Self-sacrifice”
“The man I married is not the person I live with now”
“The more you do, the more you get left to do”
“The ones that are caring are taken for granted”
“Things can get difficult because of health, mobility etc. issues but the caring goes on regardless”
“Too many expectations on the carer”
“Trying to do the best for everybody with nobody backing you up”
“We are - nameless”
“Willing sacrifice”
“Worrying a lot”
“Young carers who sacrifice their life/future”

Section 2: Theme - What Would Good Support for Carers Look Like?

Participants thought they should be given a choice about what support might be best to help them, and that all forms of support should be accessible and easily available. Some suggested that having a single point of contact for services and support for carers would help remove current barriers. Many of the suggestions were very practical such as access to training to help them in their caring role, such as moving and handling training. Getting a break from caring, at the right time, and access to a variety of breaks, activities and support to suit carers of all ages was recognised as very important. Some felt that there were challenges to getting good support and that there would need to be changes to improve this. Many respondents recognised that support from individuals or organisations that they trust and can talk openly with as essential for support to work effectively. Key themes and responses are shown below.



Some individual responses below:

"24hours helpline"
 "A challenge to get support for you"
 "A counselling service"
 "Access to respite"
 "Activities away"
 "AILN – godsend wonderful"
 "Assessment review for carers"
 "Better access to hospital/doctors"
 "Consider carers who can't get out"
 "Consistency of staff"
 "Consolidate documents currently available – too much info"
 "Contact from SA Carers Centre by phone made a big difference (telephone support)"
 "Continuity of paid care – action plans not always read"
 "Crossroads – gives the break to get out - me time"
 "Even when you get away – guilt on your shoulder, don't want to feel judged"
 "Everyone is different - not black and white"
 "Freedom from worry"
 "Future is worrying – there won't be the resources"
 "Go to centre and I feel a person again"
 "Good support relieves the pressure for the carer and the stress a bit"
 "Having a lead coordinator of services is crucial"
 "Having people to turn to so you're not alone"
 "Helpful information"
 "Home support/family support"
 "Hospital could do more for people with special needs"
 "HSCP carers should be the same staff member"
 "HSCP carers should spend more time with individuals"

"HSCP carers with people skills"
 "I am so grateful for what is already in place, particularly the therapies and charitable trust funding"
 "Impact on the life of the whole family – support"
 "Improve discharge advice/training guidance on post hospital care"
 "Improve review process"
 "Improved response time from paid carers – 1hour maximum"
 "Increased immediate respite care"
 "Just 'knowing' what help is out there for both me and my loved one"
 "Knowing what/where to go"
 "Look forward to phone call from carers centre"
 "Lots of services – need improved / joined up"
 "Mandatory training – moving/handling, medication, continence care"
 "More people just to listen"
 "More social events for carers"
 "More trained counsellors for carers"
 "Need to access the support that is needed"
 "Need to help carers to understand different issues the individual has"
 "Not feeling isolated"
 "Opportunity to get more relaxation therapy"
 "Peace of mind = good support"
 "People cannot do voluntary work to do caring role"
 "People to trust"
 "Professional supporting carer in respite care"
 "Proficiency"
 "Proper administration"
 "Recent survey experience felt to be inappropriate for my needs"

“Reliability”
 “Recognising the correct use of words/terms around carers employed/unpaid”
 “School – training for professionals”
 “SDS – my key to freedom – fabulous”
 “SDS – you don’t want that pressure, you have caring role to do - too packaged not person centred”
 “Services need to link together”
 “Sharing information – consider data protection”
 “Single point of contact for services and information”
 “Social Work department do their best but do not have the resources available, so more money available would be helpful”
 “Social work link to all carers”
 “Some initiatives are excellent – forget me not initiative”
 “Some help is available on a drop-in basis and often by referral...it took many years to find what was relevant to my / our circumstance”
 “Sort out fragmentation of services and information”

“South Ayrshire Carers Centre – great support”
 “Steeped in caring – no stamina/energy to source things for yourself”
 “Study/homework clubs”
 “Support and resource should be readily available to allow the carer to be - a person”
 “Support for over 65’s carers”
 “Support for parent carers”
 “Support group not always available or suitable”
 “Surveys about caring – tick box, repetitive not specific enough/not a direct question/trying to catch you out”
 “The role of the professional, their role is key”
 “Time away from caring role”
 “Tips on how to do practical like changing a bed with someone in it, put a jacket on”
 “Too bureaucratic”
 “Total trust”
 “Unable to share – losing so much joy”
 “We need to be acknowledged in our own right”



Section 3: Theme - What Are the Best Ways to Provide Information and Advice for Carers?

Participants felt that information and advice had to be provided in a range of formats to ensure that carers are able to get information and advice easily at the right time. They highlighted that a programme of drop-ins, outreach work and a telephone support line, could be developed, as many carers find it difficult to get the time to travel out with their area to receive information and advice. There were key areas where they felt information material should be placed, such as GP surgeries, pharmacy prescription bags, schools and local libraries. Many discussed how it had taken them a long time to find out or receive information on carer support and advice, and as such there would need to be improvements in how this information is communicated and circulated to carers. Online tools such as website, forums, social media and online videos were also considered as being important ways to provide information and advice. Many recognised that there was useful information available for carers – however as there is no single point of contact for this information – it can be difficult for carers to find out what is available. Key themes and responses are shown below.



Some individual responses below:

“24hour helpline”
“A position of understanding”
“Adverts in church magazine, OIR “
“Adverts on buses”
“Badge to identify as a carer”
“Carer friendly work policies”
“Carer is in the dark - patient confidentiality prevents important information being given to carers”
“Carers Centre – great place for signposting”
“Carers should receive all information on local area”
“Carers visit other carers – transport provided”
“Community based venues”
“Different carers all the time – don’t read notes”
“Drop-ins at college”
“Food labelling info”
“Get training on moving and handling”
“GP is an automatic link with carers and for signposting”
“Hospitals”
“If carers are identified – not always passed onto the right place or the right people – better pathways”
“If the cared for person declines care – how to manage/prove not neglect “
“Information – through local free publications - What’s On”
“Information needs to be crystal clear to be understood”
“Information needs to come to you”
“Lack of knowledge on the Carer’s Centres and what they do”

“LD providers should help carers understand caring role more”
“Leaflets / factsheets”
“Libraries”
“Local Authority should continuously speak to carers”
“Local Authority to link with 12,000 carers (census) and provide information on local support”
“Local radio”
“Major employers needed to consider their supportive role of carers”
“Marketing needed”
“Need the chance to build a good relationship”
“Newspapers”
“NHS”
“Parent line/Child line”
“Peer support”
“Pharmacy blister pack delivery service”
“Professional Care Team”
“Schools”
“Sign language”
“Social Media”
“Social Work”
“The term ‘carers’ not always understood”
“The word from fellow carers is powerful and essential”
“Third sector newsletter”
“Training people on the correct way to give advice”
“Verbally speaking to carers”
“You tube videos for carers”
“Young carers being identified”

Conclusion and Next Steps

To close the event the attendees were asked within their group tables to think of a future Ayrshire Post Headline in relation to carers. Suggestions included:

- South Ayrshire Initiative replicated nationally
- Care for Ayr - Carers Rule
- South Ayrshire leads the way – No1 in Scotland
- Carers take over South Ayrshire Council and Fresh-Ayr for Carers.

All views and opinions received at the Carers Engagement Day will be taken into consideration when drafting our Adult Carers Strategy and separate Young Carers Strategy which will be issued for public consultation in October 2018.

Going forward we will keep carers updated on what has happened via a Carers You Said, We Did campaign.