



Responding to the voice of older carers - building on what works

PRACTICE TOOL

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Introduction

The number of older carers is increasing and, for many people, becoming a carer later in life involves the transition from a more independent life to the role of a carer, when social care professionals may become involved in their lives, often for the first time. Using the voice of carers and practice experts, this publication aims to provide tools to support social care and health professionals to work effectively with older carers.

The resource draws specifically from the narratives of older carers. Illustrated by quotes from their lived experience, it includes five practice tools to help practitioners to:

- > develop understanding of what is important to older carers
- > provide timely information in the transition to becoming a carer later in life
- > support older carers to access services for themselves and the cared-for person
- > build strategies for 'being there' with older carers, reducing loneliness
- > promote and safeguard older carers' wellbeing.

It doesn't happen overnight. The cared-for person's needs develop over a period of time and before you've realised it you are spending a significant amount of time caring.

(Older carer)

This quote highlights the complexity of a transition into caring in later life, how an older person's vision for their future at this life stage can shift almost imperceptibly towards an identity defined primarily by the wellbeing of the person they now care for.

The Carers Trust (2016) report *Retirement on hold: Supporting older carers* makes a clear recommendation for early referral to carer organisations with access to a care coordinator to help older carers to navigate the health and social care system. This theme is echoed here.

The older carers' narratives underpinning this resource convey robust positivity and resilience, highlighting the strength, support and companionship of carer networks. As such, early referral is essential.

¹ A carer is considered to be 'anyone who spends time looking after or helping a friend, family member or neighbour who, because of their health and care needs, would find it difficult to cope without this help regardless of age or whether they identify as a carer' (DHSC, 2018).

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Methodology: Listening to older carers

The views and experiences of 16 older carers² were gathered and recorded via a focus group discussion at a local carers group meeting alongside four individual telephone interviews. Conversations began with an open question (“Can you tell me about your experiences?”) followed by questions to clarify what the carer saw as key points for professionals to be aware of. The discussions concluded by asking what the carer felt professionals could have done differently that may have been more helpful in their situation.

Taking a strengths-based approach (Saleeby, 2006; Romeo, 2017) and using Appreciative Inquiry as a frame of reference (Elliott, 2015), the tools seek to both build on what has worked well and to re-frame what has not worked well into what would be happening if professional relationships and services were the best they could be as described in the 16 older carers’ narratives.

The themes emerging from these discussions form the basis of the five practice tools, illustrated by excerpts from the narratives. In this way the resource aims to provide ‘hands on’ support for evidence-informed practice improvement.

Application to practice

Ford and Pike (2018) caution against a ‘focus simply on age-related service transitions’. They refer to the work of Tanner et al (2015) who emphasise that social workers should ‘realign their focus’ to understand how older people themselves perceive the transition and explore ‘the different phases ... what is being relinquished, the processes involved in making the change and establishing new beginnings ... attending to subjective and emotional dimensions of these experiences’ (Tanner et al, 2015, cited in Ford and Pike, 2018).

The tools aim to facilitate this process. They:

- > offer a guide for practitioners, supervisors and managers
- > include reflective exercises to support the application of older carers’ vision into practice
- > can be used individually, by teams or in supervision.

The final tool offers a framework for service development in line with the government’s Carers Action Plan 2018-2020 (DHSC, 2018b).

² Rather than defining ‘older carer’ by age this project refers to older carers as ‘those people who have had a change in circumstance later in life which led them to become a carer’.

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Legal context

The *Care Act 2014* puts carers on an equal footing to cared-for people and gives carers the right to an assessment based on the appearance of need. Eligibility criteria do not apply to a carer's assessment, though they do apply to eligibility for services.

The *Care Act 2014* places a duty on local authorities to:

- > prevent, reduce and delay the need for support, including the needs of carers
- > provide information and advice to carers in relation to their caring role and their own needs
- > work together with NHS partners and others in delivering the *Care Act* functions.

The new duties however, came into being in the context of ongoing financial constraint and a rapidly rising older population, intensifying the pressures on older carers (Age UK, 2017).

There are wonderful people out there working but they feel stuck with the lack of resources.
(Older carer)

Changing demographics and the Government's response from 2011-2020

Key findings of The Princess Royal Trust for Carers (2011) online survey of 639 older carers:

- > Carers aged 60–64 experience the most financial difficulty, often juggling work with caring responsibilities for more than one person.
- > The majority of older carers report caring for 60 or more hours a week – particularly those carers aged 70 or over.
- > Two thirds of older carers have long-term health problems or a disability themselves. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression.
- > One third of older carers reported having cancelled treatment or an operation they needed due to their caring responsibilities.
- > Half of all older carers reported that their physical health had got worse in the last year and seven in ten said caring had had a negative impact on their physical health.
- > More than four in ten older carers said their mental health had deteriorated over the last year.
- > Over three quarters of carers ages 60–69 said caring had a negative impact on their mental health.
- > Less than half of carers aged 70 and over who have to lift the person they care for do not feel they can do this safely and confidently.

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- > More than eight out of ten older carers have worries for the future, about what will happen to the person they care for if they can no longer care.
- > More than one third do not get breaks away from caring, and a further third get a break only once every two to three months or less.

The last census concluded that around one in ten of the population are carers (ONS, 2011), with over 1.8m carers aged 60 and over in England. These include:

- > 151,674 aged between 80–84.
- > 87,346 aged over 85.

The number of older carers is growing all the time, those aged 85 and over grew by 128 per cent in the last decade (Age UK, 2015).

Older carers have their own specific needs. They often go unidentified because they do not recognise themselves as carers or are not identified by services.

How can we improve support for carers?

In 2016, the Department of Health put out a call for evidence to hear directly from carers about the most helpful, effective and important ways the health and care sector could improve support - 6,802 people and organisations responded, carers accounting for 77 per cent of respondents. The findings form the basis of the government's response to the 2016 carers call for evidence (DHSC, 2018a) from which the *Carers Action Plan 2018-2020* (DHSC, 2018b) evolved, which aims to:

- > Increase the number of employers who are aware of caring and the impact this has on their workforce.
- > Support health and social care professionals to be better at identifying, valuing and working with carers.
- > Improve access to appropriate support for carers, including respite care and carers breaks.
- > Improve the evidence base on carers to inform future policy and decisions.
- > Ensure that the needs of carers are recognised in relevant government strategies such as *Fuller Working Lives* (DWP, 2014).

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Understanding what is important to older carers

Tool 1: Stop, Look, Listen - Think Carer

This tool focuses on what older carers told us is important in the way that professionals relate to and support them. It helps practitioners to tune in before a visit, and can be used as a guide for reflective discussion in supervision.

“The empathy side of things - for professionals to understand.”

“Everything was focused on him [a cared-for person living with dementia]. People would say, it must be awful for him. It was as if I walked around in his shadow.”

“Think about what you say, be sensitive to the lives of carers and how different they are.”

“Professionals take one small part and focus on that. If they could look at the person as a whole it could save us carers so much anxiety.”

What could professionals do differently?

“What would help? Better communication.”

“Most professionals are fantastic and they are stressed and stretched - but if you say you are going to call on a certain day make sure you do. Don't make promises you can't keep.”

“Don't say 'Have a lovely Christmas' - because I probably won't. Just take care, think before you speak.”

“Caring for someone with dementia brings its own specific difficulties. You cannot converse with the person you are caring for - it's a long slow goodbye. You need help to find others going through the same thing, that's the best support.”

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Reflective exercise: Before and After questions

Before a conversation

- > What are your thoughts before making contact?
- > What are your feelings before making contact?
- > What do you think the carer is thinking and feeling?
- > What do you think the carer is hoping for?
- > What are your plans for this conversation?
- > What are you there to help with? What do you bring?

After the conversation

- > What was the outcome of the conversation?
- > What outcomes are important for the carer as a person in their own right?
- > What do you know about the history and biography of the carer and cared-for person's relationship?
- > What impact has caring had on their relationship?
- > Does the person describe themselves as a carer, are they comfortable with this term?
- > Can you describe how the carer's relationships with family and friends have been affected by them becoming a carer at this stage of life?
- > Were you having any internal reactions during the conversation that you did not share? What were they?
- > In light of this reflection what is your overall summary of the carer's strengths and support needs at this time?
- > What would be a successful outcome of your next conversation from the carer's perspective?
- > What would be a successful outcome from your perspective?
- > In light of the reflections you have made so far are there any things you might do differently next time or in your work with other carers.

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Ten Top Tips

1. Tune in to the carer's world before you ring or visit, be ready and prepared to really listen and empathise.
2. Think about your greeting – is a casual “Hi, how are you today?” sufficient?
3. Expect interruptions, be flexible. Remember the carer is likely to be multi-tasking and may be very stressed.
4. Keep simplicity of process – don't give too much information at once.
5. Don't leave a list of services expecting the carer to be able to navigate the system.
6. Make sure the carer is aware of local peer support groups and has access to reliable substitute care to attend.
7. Check their GP and surgery staff are aware that the older person is a carer and that any reasonable adjustments have been made for them both to access health services.
8. Check appropriate information-sharing processes are in place.
9. Ensure the carer knows who to contact in an emergency³.
10. Ask for feedback - has the conversation with you been helpful?

³ www.carers.org/article/emergency-schemes-carers

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Providing timely information in the transition to becoming a carer later in life

Tool 2: Person-centred timeline

The following practitioners' tool enables you to talk about the future in whatever way is helpful to the carer at this time, starting to think through how things will change and what they might want to happen. You can use it to give information at the carer's pace, recognising that they may not yet be ready to talk about the longer-term, nor consider themselves a carer.

"I was new to caring so I went to a carers course to meet people with similar experience. They did a role-play of end of life. It was awful, I didn't go back."

Me now

How the cared-for person's support needs affect me now?

What is important to me as a person in my own right?

The near future - as things change a bit

How caring for them might affect me in the near future?

What might help me to still do the things I like doing?

The medium future – as things change a lot

How caring for them might affect me?

What will be important to me?

The far future

How caring for them might affect me?

What will be important to me?

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What older carers told us

These experiences may help you to begin to draw up a list of personalised support services with the carer.

“Getting away for any amount of time is difficult – I haven’t had a holiday for eight years. Having help to arrange regular, consistent respite care is invaluable. It must be something that the cared-for person can then get familiar with.”

“The day service won’t have him back [now the cared-for person has developed more complex behaviour]. It makes it hard for me to cope. There needs to be in-between care, something between residential and day care services – day services that can cater for more complex behaviours.”

“You’re not going to ask for a lot in the early stage but having support just getting into the system in the early stage is very helpful. Then it’s there when you need it.”

“What helps? Having someone to really listen and understand and then find services to match.”

“I don’t have any time now without being interrupted. The only time is when she’s asleep but that is unpredictable too. The thing that would help most is substitute care and having support to help to arrange this.”

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You can begin to list support services that might be helpful here:

Support services in the near future

Support services in the medium future

Support services in the far future



Reflective responses

- > Many older carers would never use the term carer, even if they plainly are one, as this is not how they wish to view their role, and it positions the cared-for person in the role of a dependent person who needs help which they may not be willing to locate themselves in. None of this diminishes their right to be recognised and supported. Offer support carefully whilst being mindful of language and respecting their right not to be called a carer.
- > Consider the changing capability of the carer over time as well as the cared-for person – the carer is ageing too, and may be (or become) in need of care themselves, particularly with the added demands of the caring role.
- > Start by focusing on existing networks and familiar community resources which could be built upon.

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Supporting older carers to access services

Tool 3: Building a Triangle of Care between the carer, cared-for person and professionals

The following practitioners' self-assessment tool aims to help you and/or your team to measure where you are in relation to supporting older carers to access services, and to identify how you can improve. It is based on an excerpt from the *Triangle of Care*, a resource developed by the Carers Trust and the Royal College of Nursing (2013) using the Red, Amber, Green system.⁴



⁴ The full resource is available online: https://professionals.carers.org/sites/default/files/the_triangle_of_care_carers_included_best_practice_in_dementia_care_-_final.pdf

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The Triangle of Care – six standards

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are ‘carer aware’ and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing information are in place.
4. Defined post(s) responsible for carers are in place.
5. A carer introduction to the service and staff are available, with a relevant range of information across the care pathway.
6. A range of carer support services is available.

(Carer’s Trust and Royal School of Nursing, 2013)

This tool is focused on Standards 5 and 6 - Supporting access to services

	Criteria	R	A	G	Where are we now?	Action Plan	Evidence of achievement	By whom?	By when?
5.1	On initial contact with services, or on initial identification of an older carer, the carer and cared-for person are given an introductory letter that explains the core services and points of contact.								
5.2	An information pack which outlines specific services for carers, including specialist support for older carers, is made available.								
5.3	Policies and procedures about carer involvement and information about older carer support are made readily available and clearly advertised.								
5.4	Meeting and greeting protocols are in place to offer support, reduce distress and address concerns of older carers.								
5.5	Older carers are offered an early appointment to hear their story, share information about the person they care for and address concerns.								
5.6	The cultural and language needs of a diverse range of older carers has been addressed in the preparation of the information pack.								
5.7	The format of the information pack is flexible and regularly updated.								
5.8	A named member of your team is made responsible for commissioning, storing and issuing packs.								
5.9	Your team offers all carers the opportunity to have a conversation and encourages them to access support.								

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	Criteria	R	A	G	Where are we now?	Action Plan	Evidence of achievement	By whom?	By when?
5.10	All carers are involved in the planning process and are clear about what to do if in need of help.								
5.11	All carers are regularly asked for feedback regarding the service provided as part of service monitoring and improvement.								
6.1	Dedicated peer and older carer support services are available locally and the carer is aware of them.								
6.2	Local advocacy services are available for older carers and for people with dementia and the carer is aware of them.								
6.3	All carers have access to one-to-one support when needed.								
6.4	The need for support is discussed with the carer and the cared-for person.								
6.5	A new carer is automatically offered a carer's assessment and support plan which includes the need for support and identifies any areas of risk.								
6.6	A referral is made to local services for carer support where required.								

“The carers meetings happen while the local dementia group is on for the cared-for people. That really helps – having a safe space to talk while the cared-for person is looked after next door.”

“What would have helped? At an early stage to have the reassurance that there is a team that can be reached in an emergency.”

“What could professionals do that would help? Early signposting and being made aware of what is available in your local community. I only found out about the carers group by chance.”

What can professionals do differently?

“The local bus which a lot of people used to get to the GP surgery has been cut – there are a lot of people putting pressure on the bus company to change.”

“What helps? Being able to talk through with people in similar situations, it gives you ideas.”

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Questions for reflection

What are the potential barriers to older carers being able to access services in your area?

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What can you do more of to support them?

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What will you put in place to help move the criteria you have marked as red or amber towards green?

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Building strategies for ‘being there’ with older carers

Tool 4: Reducing loneliness

Building a trusting relationship and ‘being there’ alongside older carers is pivotal. It is essential to have more than a one-off assessment visit from a social worker or other social care professional; it is only then that a carer may be willing to talk about their sadness, loss, loneliness, fatigue or concerns about the future. It is part of our public duty to help carers to recognise when to explore longer-term options, and offer ‘permission to stop’. The worker relationship is crucial to carers feeling able to talk openly about the issue of ‘giving up’ and feelings around this. These conversations need to be had carefully. Support for older carers through this process, and beyond the transition of the cared-for person into longer-term care, is critical - especially in the context of dementia, as illustrated by the carers’ quotes below.

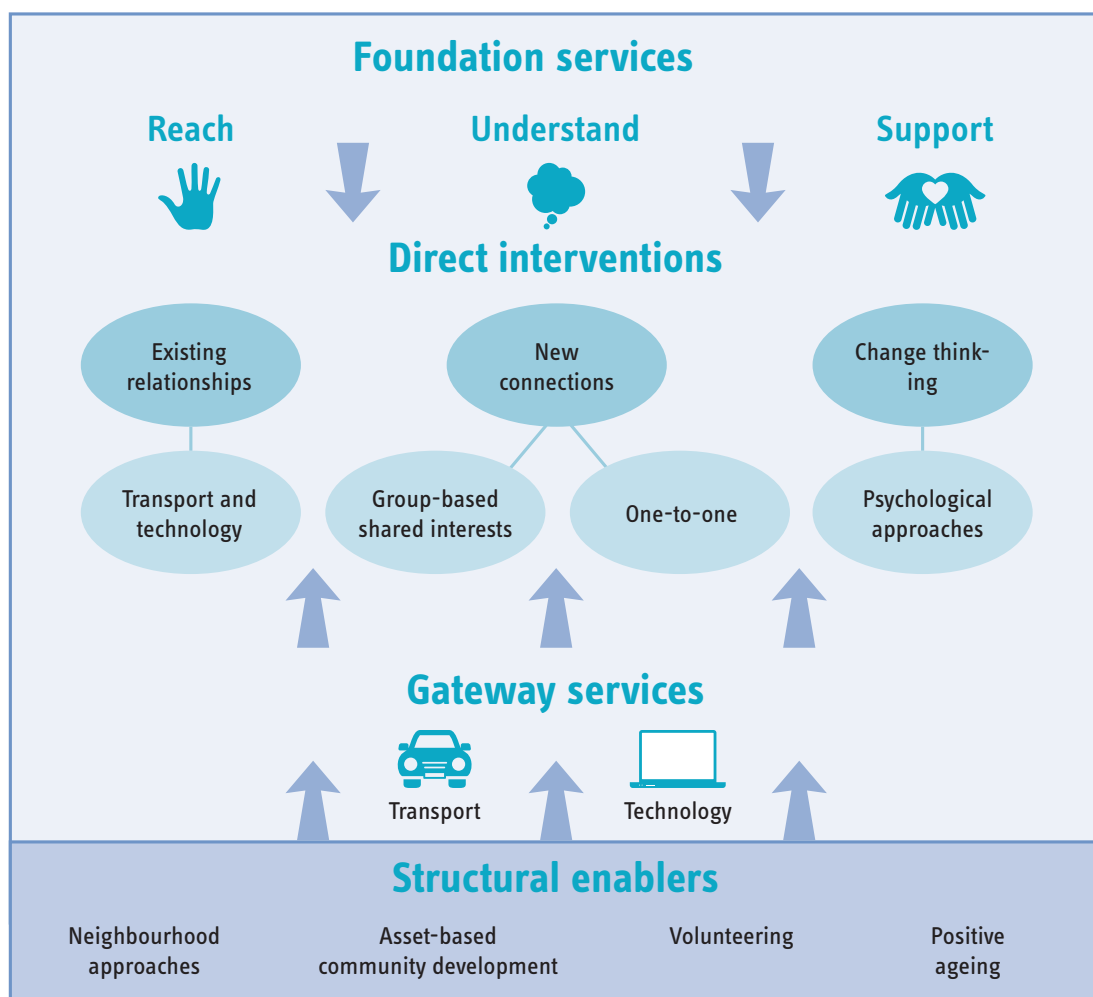


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Research investigating the emotional wellbeing of older carers highlights ‘the day-to-day realities faced by many older carers, including a high risk of emotional distress; the loss of friends, either because of a lack of time to socialise or because friends were unable to properly understand the constraints and strains of caring; and potential health risks’ (ILC, 2015). Their report recommends that:

- > More needs to be done to help older carers maintain their social networks and to provide them with breaks from their caring duties.
- > GPs should be made aware of the high potential for depression among older carers, and assessments of their mental health should be made routine.
- > Local authorities should promote local groups, activities and volunteering opportunities for bereaved carers so that they are aware of what is available.



⁵ Based on Age UK and The campaign to end loneliness (2015) Promising approaches to reducing loneliness in later life: www.campaigntoendloneliness.org/lonelinessresearch

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Questions for reflection

How are you supporting older carers to:

- > Maintain existing relationships?
- > Take up services that help them to make meaningful connections?
- > Access transport and technology as a gateway to enabling social connections?
- > Make decisions for the longer-term?

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How can you improve neighbourhood approaches and asset-based community development?

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“During Carers Week we held an open session for carers – no carers turned up but there were GPs, nurses, other frontline staff. I explained the situation – that carers might have to pay a lot for someone to care for a cared-for person.”

“I know a carer who paid someone to look after his wife while he attended a GP appointment and the GP was running late which led to more cost and the person feeling very stressed when he saw the GP.”

“When my husband had a stroke I didn’t get any support when he came out of hospital. There was no aftercare. I didn’t know what to do. It was only later that I found out about care groups and was introduced. Most of the information I’ve had comes from the carer’s group.”

“There are barriers all over the place. I said I was happy for an appointment with a nurse but was told you need a doctor to say you need to see a nurse!”

What could professionals do differently?

“Once I found the carers’ group they told me about ‘Message in a Bottle’⁶. This is like a contingency plan so that if you’re taken ill it tells people you’re a carer and what to do.”

“You need to know who to contact. I had a Macmillan nurse who was good for one month and then disappeared. I couldn’t contact her and I didn’t get a replacement. I was told to phone the hospital which is open working hours on weekdays. There is no help if something happens out of hours. On a Bank Holiday I called eight numbers trying to reach someone.”

“In my experience it was very difficult to find cancer support. I was told about which benefits I could claim but otherwise I wasn’t given much information. I have a different GP to my husband so the GP didn’t want to give me any information either. Information needs to be shared.”

“I have compiled an information book of top tips for supporting carers – there’s information for doctors and nurses as well as general information and we have given them to the surgery.”

“What would help? Being registered as a carer with your GP. If you need a double appointment you can say ‘I’m a carer’ and that you need this so you don’t get the usual third degree about why.”

⁶ Carer’s Trust: www.carers.org/article/message-bottle - where you keep essential personal and medication details in a small bottle in the fridge.

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Tool 5: Promote and safeguard older carers' wellbeing

This organisational audit tool is based on a summary of carers requests in the *Government response to the 2016 carers call for evidence* (DHSC, 2018a) with reference to the *Carers Action Plan 2018-2020* (DHSC, 2018b). It aims to support commissioners in setting SMART goals to support older carers, identifying specific actions for allocation to a named person, ensuring that review dates and processes are agreed.

Carers' most frequent requests (DHSC, 2018a)	How is this being achieved for carers aged 50-69 in your locality?	How is this being achieved for carers aged 70-79 in your locality?	How is this being achieved for carers aged 80+ in your locality?	Current overall rating (1-5 scale) and next steps for improvement (DHSC, 2018b)
Provide more information and training for health, social care and education workers to help them identify unpaid older carers and provide information.				
Identify older carers as early as possible, at the time the person cared-for is diagnosed or in subsequent appointments.				
Make/use a directory of local services easily available to older carers and keep it updated.				
Provide information and support using a variety of formats and approaches, to recognise the diversity of older carers and their wide range of needs. Give older carers access to consistent, good quality respite care (including house-sitting services).				
Give older carers information about their eligibility for financial support.				
Give older carers an appropriate level of financial support, set at a level that recognises the amount of time and effort they put into caring and the impact that this can have on other sources of income.				
Provide older carers with someone to speak with regularly to air their concerns and 'let off steam', including peer support, counselling and/or a named link worker.				
Work with the local authority, voluntary and community sector to improve support to older carers.				
Raise awareness of older carers support needs amongst employers, the public and professionals.				

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Key messages for commissioners

Older carers consistently told us that what would help is:

- > Bridging the gap between day and residential services for those with more complex behaviour. For example, providing individual support workers for the person in the environment they feel familiar and comfortable with.
- > More peer support services locally (for example, older carers support groups) with support for the cared-for person on site (for example memory groups alongside carers groups).
- > Respite services which offer more flexibility for pre-arranged respite at times that best support the carer, and in an environment familiar to the cared-for person.

The Carers Trust (2015) refers to research which indicates that LGBT carers and those from black, Asian and minority ethnic backgrounds may be less likely to be identified by social care services and less likely to take up services. They highlight the importance of:

- > targeted work to reach and support marginalised carers ⁷
- > joint work with local voluntary groups supporting people from different parts of the community to reach carers from diverse backgrounds.

Final summary

Where the person is found to have no eligible needs, local authorities must provide information and advice on what can be done to meet or reduce the needs (for example what support might be available in the community to help the adult or carer) and what can be done to prevent or delay the development of needs in the future. Local authorities should consider how this package of information can be tailored to the needs which the person does have, with the aim of delaying deterioration and preventing future needs, and reflect the availability of local support.

(DHSC 2018c)

⁷ See reference list for resources on supporting marginalised carers

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The Care Act 2014 (DHSC, 2018c) and current statutory guidance on supporting carers (DHSC, 2018b) make it clear that assessment must be completed on ‘appearance of need’ regardless of financial circumstance. When an outcomes-focused approach is used this supports older carers to access information about services and to navigate their way into a personalised network of support which meets their needs.

Older carers told us that having the support of other carers matters most to them, together with help to find services. They told us they value practitioners who take the time to listen to and understand them and their lives.

Practitioners who are sensitive to the lives of carers build positive relationships with carers and achieve the best outcomes through:

- > Taking their lead from carers and providing support and information at the carer’s pace.
- > Using interpersonal skills to understand what life is like for the carer and continually adapting their approach to meet the carer’s changing needs.
- > Being flexible and understanding that carers may be under immense stress and may find it hard to find time for meetings.
- > Supporting the carer’s wellbeing, for example thinking about how the carer’s social relationships and interests might be maintained and supported alongside their caring role.

Responsive practitioners support carers to ensure their GP knows about their caring role in order that their own health needs are met. They also take a rights-based approach to empower carers to know about what they can expect from services and how reasonable adjustments may be made under the *Equality Act* (2014).

Key message

All health and social care professionals, including first point of call receptionists, need to be aware that older carers may or may not recognise their role as carer nor be aware of the support they and the cared-for person are entitled to in accessing services in the community. This practice tool aims to aid practitioners, managers and leaders to be proactive in identifying, supporting and caring about all older carers.

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Older carers told us they feel supported by:

- > Professionals who are in tune with their situation.
- > Kindness and a sympathetic ear.
- > Early access to peer support groups, time to talk with those in a similar position.
- > Advice and guidance to help navigate support services.
- > Knowing the cared-for person is well looked after by substitute carers so they can attend carers' support groups and take regular breaks for themselves.
- > A GP and health services responsive to their needs.
- > Appropriate information-sharing processes.
- > Familiar, consistent, affordable, regular and reliable respite services.
- > A range of ways of accessing services and carers support, flexible times.
- > Out of hours help and a named professional to contact in a crisis.
- > Their views being sought and feedback acted upon.

This Practice Tool is based on the detailed narratives of older carers and the richness of their feedback for which we are immensely grateful.

You can listen to carers talking about their experiences in our podcast with older carers via this page on the Research in Practice for Adults website: www.ripfa.org.uk/resources/podcasts

Resources for frontline practitioners and managers who are working with carers can be found at: carers.ripfa.org.uk

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Responding to the voice of older carers – building on what works

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PRACTICE TOOL

Responding to the voice of older carers – building on what works

Supporting marginalised carers

www.carers.ripfa.org.uk: Case ‘Susan’

www.coercivecontrol.ripfa.org.uk: Case ‘Ayesha’

<https://dementia.ripfa.org.uk/practice-guidance/uphold-peoples-rights>

Other useful resources

Carers Trust *Speak up for older carers*: <https://carers.org/speakup>

Carer Research and Knowledge Exchange Network: www.open.ac.uk/caren

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