

Guidance for GP practices on Anticipatory Care Planning conversations with people with dementia living in the community during COVID-19 (August 2020)

- 1 Before you have a conversation with a person living with dementia about anticipatory care planning (ACP), it is important to consider whether the conversation is **necessary** during this time of physical distancing.

There are some very specific positive reasons why it may be important to consider ACP conversations for people with dementia. People living with dementia in general are at increased risk of a sudden deterioration in their health, and many will have less resilience to infection. There may be capacity issues (in relation to making decisions during a deterioration), which make it difficult for health professionals to know what care and treatment to provide in the event of a sudden illness or an emergency. These general considerations should be borne in mind but of course a person-centred approach is important.

ACP conversations can be a comfort to the person with dementia and those close to them. However, if conducted in the wrong way they can become upsetting and can undermine good intent.

If the conversation is not necessary, do not pursue it.

Taking time to consider preferences, priorities and specific care plans in advance of any deterioration is of particular importance for people with dementia. It is important to know who the person with dementia would like to support them to make decisions during a deterioration. It is crucial that **unpaid carers** and other people important to the person with dementia are involved in discussions around care and support alongside their loved one.

You should be aware that unpaid carers have their own needs and should be fully supported in their caring role. For more information on unpaid carers' rights to involvement and support, and relevant resources, please see the Annex.

Although unpaid carers, family and friends should play a key part in those discussions where possible, they do not have the right to make decisions on behalf of the person with dementia unless they have the appropriate Power of Attorney.

You should check whether there is already an Anticipatory Care Plan (ACP) in the person's records (this may be recorded in the Key Information Summary KIS and special notes) and decide whether it is sufficient or whether it needs updated.

If you are unsure whether a conversation is necessary, see the 'Anticipatory Care Planning Toolkit - Let's think ahead' (Healthcare Improvement Scotland ihub):

<https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/frequently-asked-questions/>

- 2 Wherever possible, **avoid talking by telephone**. Telephone can deprive the person with dementia of context - it makes it difficult to see who they are talking to and may make the conversation difficult to understand.

Consider the use of NHS Near Me (video consultation) as an alternative to telephone where face to face, physically distanced, conversation is not possible. This will not be suitable for all people, but it may work for those at an earlier stage of dementia who are able to use a smart phone or tablet and have access to wifi. The person with dementia may prefer that you speak with someone who is their carer, family or friend to decide the best way to have Anticipatory Care Planning (ACP) conversations. You will need to use your professional judgement and a degree of common sense.

The ACP conversation should be led by the most appropriate clinical professional in each case. This should be someone who knows the individual well and is experienced in having ACP conversations. This may be a doctor, a community psychiatric nurse, an advanced nurse practitioner or relevant allied health professional who fits this role.

- 3 You should check whether there is a record of anyone registered as the **Welfare Power of Attorney** for the person with dementia. This is someone who has been given the legal power to make decisions on the person with

dementia's behalf when they are unable to do so on their own. A Welfare Power of Attorney covers decisions about health and personal welfare. Again, decisions on behalf of a person with dementia can only be made by someone with the appropriate Power of Attorney.

If there is a Welfare Power of Attorney on record with your practice (within the patient's medical record or KIS) you should contact them in the first instance, rather than the person with dementia. They will be able to offer valuable advice on how you might approach a conversation, e.g. what might work well, or the best time of day to talk.

Wherever possible, you should have the conversation with the person with dementia and the Welfare Power of Attorney **together**.

- 4 If you have been unable to locate an Anticipatory Care Plan (ACP) or (KIS), check with the Welfare Power of Attorney to ask if one is **already in place**. If it is, find out where it is kept and check if it needs updated.
- 5 If the **person with dementia** has capacity to make welfare decisions, consider if it is possible to meet with them face to face. This could be achieved while still maintaining safe physical distancing. The person may wish to have a trusted carer, family member or friend with them and you should let them know that this would be welcomed.

Also consider any other relevant factors, e.g. whether the person is a British Sign Language user, or whether they speak a language other than English. Reasonable adjustments should be made to enable a good conversation, e.g. interpreters.

- 6 Conversations should be **specific and clear**. It is best to outline at the beginning of the conversation what you wish to discuss and, importantly, why. Where possible, avoid using professional jargon or language that might be considered patronising. Remember that not everyone with dementia will be aware of what COVID-19 is or what it means for them. The involvement of unpaid carers will be important in these discussions.

Be prepared to repeat what you have said so that everyone understands what is being discussed and can respond as fully as possible. Consider using health literacy techniques such as 'Teach back' and 'Chunk and Check' to ensure that you are being understood. Allow enough time for a meaningful conversation.

If someone is struggling with the conversation, it may be helpful to take advice from a Speech and Language Therapist or to use a communication tool, such as Talking Mats (www.talkingmats.com).

- 7 During the conversation, **look at and speak to the person with dementia** directly rather than their family/friends. Really listen to what is being said and ask questions if you do not understand the responses given. Family/friends are there to support, offer gentle encouragement and help clarify where necessary.
- 8 Take a **person-focused approach**, helping them describe their values and preferences: "What is important to you?"; "What is important to your family?". Listen to what they say about their family or personal history, their likes, interests, beliefs. Listen out for anything they feel particularly strongly about.
- 9 **It will often take more than one conversation** to conclude any Anticipatory Care Plan (ACP).
- 10 If a conversation is proving to be **upsetting** to the person with dementia, or if they clearly do not understand what you are saying, steer the conversation in another direction and conclude it.

The conversation could also be upsetting for any unpaid carer, family member or friend who is present. You may be able to continue the conversation with the person with dementia alone or it may be best to reschedule it for another time. If the person who is upset has Power of Attorney, you should not continue the conversation without them or another person with Power of Attorney present.

Consider what has been achieved through the conversation and whether a further conversation is absolutely necessary. If so, it might work better another day or in another way.

Useful resources

- EC4H – COVID-19 Effective communication for professionals (RED-MAP resources)
<https://www.ec4h.org.uk/covid-19-effective-communication-for-professionals/>
- Anticipatory Care Planning for COVID-19 (Healthcare Improvement Scotland ihub)
<https://ihub.scot/improvement-programmes/living-well-in-communities/anticipatory-care-planning/covid-19-anticipatory-care-planning/>
- COVID-19 and communication for people living with sensory loss (Health and Social Care Alliance Scotland)
<https://www.alliance-scotland.org.uk/blog/news/covid-19-and-communication-for-people-living-with-sensory-loss/>
- The Health Literacy Place – Health Literacy Techniques
<http://www.healthliteracyplace.org.uk/tools-and-techniques/techniques/>

UNPAID CARERS' RIGHTS AND RESOURCES

An unpaid carer is defined as anyone who provides, or intends to provide, non-contractual care to someone else. This means it excludes people who are providing care as part of a contract (e.g. paid work) or through volunteering. Carers can be family members, friends or neighbours.

Duty to involve carers

Under the Carers (Scotland) Act 2016, local authorities have a duty to involve carers in assessing the needs of the person being cared for. The extent to which they are willing and able to provide care must be taken into account. Carers are often able to contribute valuable insight about their caring role and the person they care for, which is why it is so important to involve them.

NHS Education for Scotland and the Scottish Social Services Council has produced a helpful guide, '[Equal Partners in Care](#)', to support professionals identify, support and involve carers in conversations about the person they are caring for.

Carers' rights to support

Unpaid carers also have a right to support to help them look after their own wellbeing under the Carers (Scotland) Act 2016. Their needs and the needs of the person they care for may not be the same. Normally, local authorities have a duty to offer carers a personalised support plan and carers also have the right to request one. This right to a personalised plan has been temporarily suspended in some areas where it would mean a delay in people getting the support they need.

This plan will identify what is important to the carer. If any of their needs for support, as identified in the plan, meet the local eligibility criteria then they have a right to support to meet those needs.

Emergency and future planning

Through the development of their personalised plan, carers will be asked whether they have arrangements in place for the provision of care to the cared-for person in an emergency, for example, if either the carer or the person with

dementia is affected by COVID-19. They will also be asked whether there are arrangements in place for the future care of the cared-for person.

A toolkit called '[Picking up the Pieces](#)' has been developed by ENABLE Scotland to support carers develop their own emergency plan.

Local carer centres are also well placed to support carers to develop these plans.

Signposting to support

When engaging with unpaid carers for ACP purposes, it will also be helpful to provide them with information on these rights and signpost them to their [local carers centre](#) which can help them to find out more about what support is available for them.

For further information on carers' rights under the Carers Act, please see the [Carers' charter](#).

[Leaflets](#) to help carers understand what to expect under the Carers Act are also available.