



PARTICIPANT Recommendations



Cheshire West and Chester Council and the NHS working together



These recommendations come from people with lived experience of managing long term conditions or of caring for a loved one with long term conditions. They have expert experience of accessing care and support services locally and empathy for experience is the starting point for good service design.

During the appreciative inquiry participants have been asked what has worked well in the past or now to manage their conditions and how the whole system could work in the future to support and manage their needs as well as possible.

Overwhelmingly, participants have said that they want to be treated with dignity and respect and want to be able to get the right support, at the right time and in the right place to be able to self care as well as they are able to.

Participants have come from all care communities, with a wide range of long term conditions and a wealth of experience in managing those conditions. They have committed over 1,200 hours to the community conversations which took place in spring 2019.

The recommendations in this document are a summary of the main recommendations that have come from all of the care communities and the words are as close to the participants words as possible. The detailed recommendations for each of the care communities will be in the final report to be presented at the end of July 2019.

Facilitated by Cheshire Community Action



General Care and Support

-  Have systems that enable continuity of care with the same GP who understands people's conditions, has a better understanding of them as a whole person and is able to take a more holistic view of how they can be supported to manage their conditions.
-  Make it easier for us to get a GP appointment when we need one. Automated telephone systems and receptionist triage mean that often we can't and this makes it more difficult to self care. We understand when something about our conditions has changed and when we need to see a GP urgently. It would be better if triage was carried out by someone with medical knowledge.
-  Be able to get longer appointments with GPs when you have complex conditions. Ten minutes often isn't enough time and a longer appointment would avoid having to make numerous repeat appointments.
-  Have designated sessions at GP surgeries for walk in clinics where no appointment is needed.
-  Offer appropriate emotional and psychological support to people when they are diagnosed with an incurable long term condition to help them to understand their condition, how it might progress and what support is available to help manage it.
-  Have systems that enable patient records to be linked and accessible across primary and secondary care so that the clinician has a full understanding of our conditions and treatment.
-  Ensure carers' needs are assessed and more support, including more respite care, is available to carers and partners of people with long term conditions to enable us to support the person we care for as best we can for as long as we can.

-  Listen to the carer's point of view which is different to care organisations' points of view.
-  Notice when people are socially isolated and refer them to appropriate support.
-  Have pharmacists based at GP surgeries to get advice on medication, potential side effects and to carry out medication reviews.
-  We should be able to have a choice when there are similar types of medication available and should be provided with information about alternative or holistic therapies and the importance of diet and exercise.
-  Enable better signposting to other support services to support us to manage long term conditions. There is good signposting and support after an acute event such as a stroke, but not for many incurable conditions.
-  Have quicker referrals to pain management clinics and better advice on holistic treatment to enable us to manage chronic pain conditions better.
-  Have more direct access to wellbeing co-ordinators to enable us to access non-medical support to help manage our conditions.
-  Have better training for all staff about suicide and who people should contact for help and support.
-  Have better training for all staff about the importance of self care and how to promote it.
-  Involve us when designing surgeries to ensure the design meets our needs, particularly in relation to accessibility, seating, confidentiality and having a welcoming environment.
-  Make it easier to access home care in rural areas because the stress of not being able to impacts on the conditions we're living with.



Specialist Care and Support

- More specialist services and clinics should be delivered as close to where we live as possible. Can specialists travel to see groups of patients rather than lots of patients having to travel to see specialists?
- For group courses for patients, such as diabetes courses, it would be better if the providers travelled and put on courses locally rather than a dozen patients and their carers having to travel.
- Have more clinician led advice and support groups locally such as for diabetes, breathing, pain management and diet to help us to manage our conditions better ourselves.
- Have specialist nurses that are accessible locally to support people with long term conditions. For example, it worked much better in the past when there was a local Parkinson's/Neurology nurse who could be easily contacted for advice and support rather than the current system having to wait for responses from specialists outside of the area.
- Be able to access respiratory nurses when we need to not just through an appointment system.
- For people with multiple conditions, it would be better if consultants planned treatment and care together in multi-disciplinary meetings to enable us to understand holistically what treatment we will be having and what we can do to manage our conditions better ourselves.
- There should be better systems for quickly sharing notes and information between consultants and GPs. Delays can lead to conditions getting worse.
- Use Hospital at Home where possible to avoid unnecessary hospital admissions or prolonged stays and make it available when an initial admission has been made to a hospital outside of the Borough, for example, to Arrowe Park.
- There should be mental health specialists based within GP surgeries particularly for people whose mental health suffers as a result of their condition and the things they are no longer able to do.
- Have better access to personal health budgets that are tailored around individual needs to help us to self care.
- Talking therapies should be more widely available and low cost/free to provide support whilst we are waiting for CBT or counselling.
- Have access to a crisis centre where we can get professional support, access therapies and get information and support from a peer support worker.
- Get physiotherapists to work with personal trainers to enable them to understand our conditions and support us to manage them.
- Take account of the transport difficulties people face in rural areas and the impact on our ability to access services.





Community Support

- Have more community based and community led peer support groups that enable us to meet, share information, get a better awareness about managing our conditions and support each other. Support groups could take a holistic approach, recognising the link between physical and mental health and enabling us to share coping mechanisms. Support would be needed to help us to run these groups e.g. training, access to meeting spaces or help with room hire costs and access to specialist nurses and therapists to visit the groups and give advice.
- Carers support groups could run at the same time as support groups for people with long term conditions to make it easier for carers to attend. The groups should however run separately because each need different outcomes from the groups.
- There should be more community based support for carers and better promotion of what is available.
- Better access to hydrotherapy pools, particularly warm pools for people with conditions like arthritis and fibromyalgia, and exercise programmes with appropriately trained instructors would help us to keep active and maintain strength.
- Have more social groups and activities, particularly exercise and movement activities, where there is a strong emphasis on making us feel welcome.
- More exercise classes should be available in small groups for people with neurological conditions such as Parkinson's.
- Have a holistic therapy hub where we can access affordable holistic therapies, acupuncture, massage and advice on nutrition, diet and exercise.
- A buddy system could be developed where people could be paired up with someone who has experience of the same condition and can give support.
- Have more support for older people with long term conditions such as buddies and volunteers to provide practical help and support.
- Have trusted people in the community that can help people with long term conditions to navigate the system.
- Have community based workers who we can go to to talk about our conditions and get support. Someone who is trusted and non-judgemental and can help us to network and set up support groups.
- Provide support to get affordable access to gyms.
- Have a campaign to raise awareness about self care and caring for someone with long term conditions.
- Hold community events that bring people together and raise awareness about conditions and how to manage them.
- Have activities that would help people to get back into work that they could manage to do with limiting long term conditions.
- Provide information and education for businesses/ employers to improve their understanding of how they can support employees with long term conditions.
- Have local support to enable people with long term conditions to engage in activities in their community, to volunteer and to keep active.
- Encourage young people to help with community support.





Information

- Information that helps people to self care should be in plain language and accessible locally in print, in person, by telephone as well as online and should be accessible for people with additional needs.
- There should be one local website that has consistent, up to date information about long term conditions and how to manage them, what is available at each GP surgery, what other care and support services are available locally and wider community support such as support groups, exercise classes and activities. Information from the website should be printer friendly so that it can easily be printed off for people who prefer written information.
- A system that shows the services that are available for particular conditions and for carers would make it easier to navigate.
- Local information hubs should be available where people can access information on a drop-in or pre-arranged basis. These could be in existing services such as GP surgeries, pharmacies, Council offices, libraries and community based services. Local people could be trained to support people to access information through these hubs.
- How to access local information should be widely promoted through local shops, cafes, community centres, newspapers, local magazines/newsletters, post offices, libraries and through services that have a wide reach such as in supermarket deliveries.
- Information packs could be given to people when they are diagnosed with a condition to help them to understand about managing their condition and what support services are available.
- Information should be provided to patients about the support that is available if long term conditions deteriorate to enable us to plan ahead.
- GPs and pharmacies should pro-actively provide information about self-help groups, voluntary groups and events that are coming up that could help us to manage our conditions.
- Awareness should be promoted about the range of support pharmacies can provide, particularly about advice on treating minor ailments, medication and side effects and how combined medications can affect each other.
- Use TV screens in GP surgeries to promote information about self care and local support services.
- Have more information about medication and possible side effects in larger writing and on line to enable us to have a better understanding of our treatment.
- Improve information about accessing telecare, for example, alarm buttons if you fall.
- Have more information about how we can access services more efficiently at our GP surgery, such as e-consult.
- Have consistency of GP e-services across care communities.