"LIVING RIGHT UP TO THE END" WHAT DO PEOPLE WANT TO SUPPORT THEM TO MAKE PLANS FOR END OF LIFE?

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Background

National policy encourages people with Long Term Conditions (LTCs) to plan for end of life (1,2). There is evidence that Advance Care Planning can improve the quality of patient –clinician communication, reduce unwanted hospitalisation, and increase patient satisfaction and quality of life. (3) Healthcare Improvement Scotland recently launched the Anticipatory Care Plan Toolkit along with a programme of training for health and social care professionals. This document acknowledges the need for "a cultural shift and change in the way we work to develop a robust community infrastructure" (4:5)

Aim

To identify what is important to people living with Long Term Conditions in order to support them to self- manage and maintain control of their own dying.

Methods

A co-production approach was used in order to "shift the decision making from 'top down' expertise to a more genuine and equal engagement amongst various parties who are interested in how people's lives are shaped and lived" (5:3)

Eighteen community engagement events were held in local venues. People with LTCs and carers were invited to discuss three questions:

1. What matters to you when you are living with declining health?
2. What prevents you making plans for the future?
3. What would help you to plan for the future and what support do you need to do this?

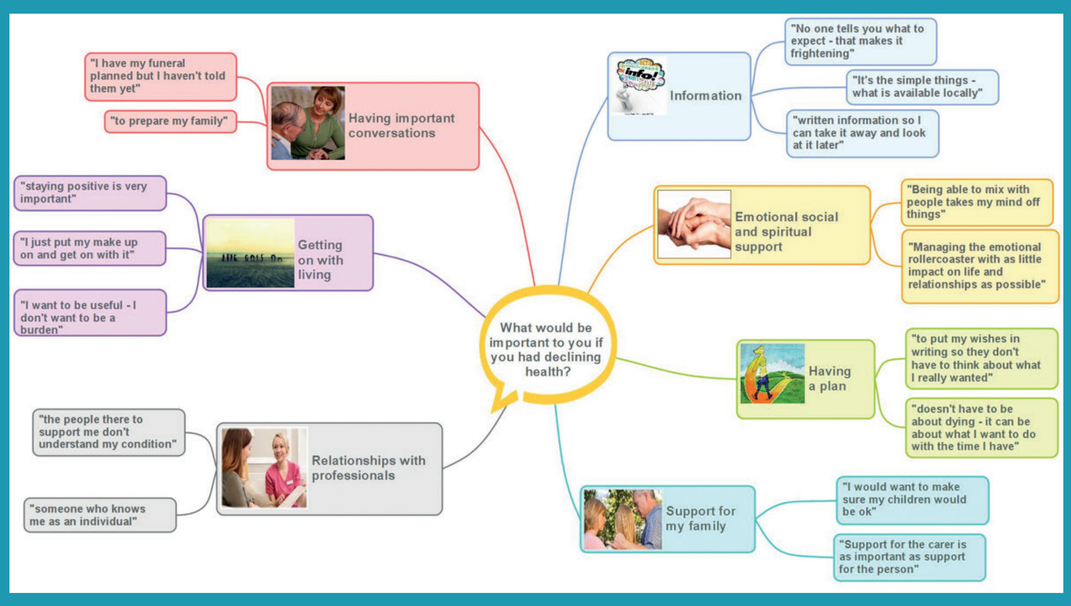
In the initial phase of engagement we listened to the views of 348 people. 114 people were living with LTCs. 100 identified themselves as carers. Many of these carers were also living with long term conditions. 134 people provided support in their community for people with LTCs either individually or in groups.

Data were collected by consented audio recording, note taking and post-it notes depending on the preference of the group.

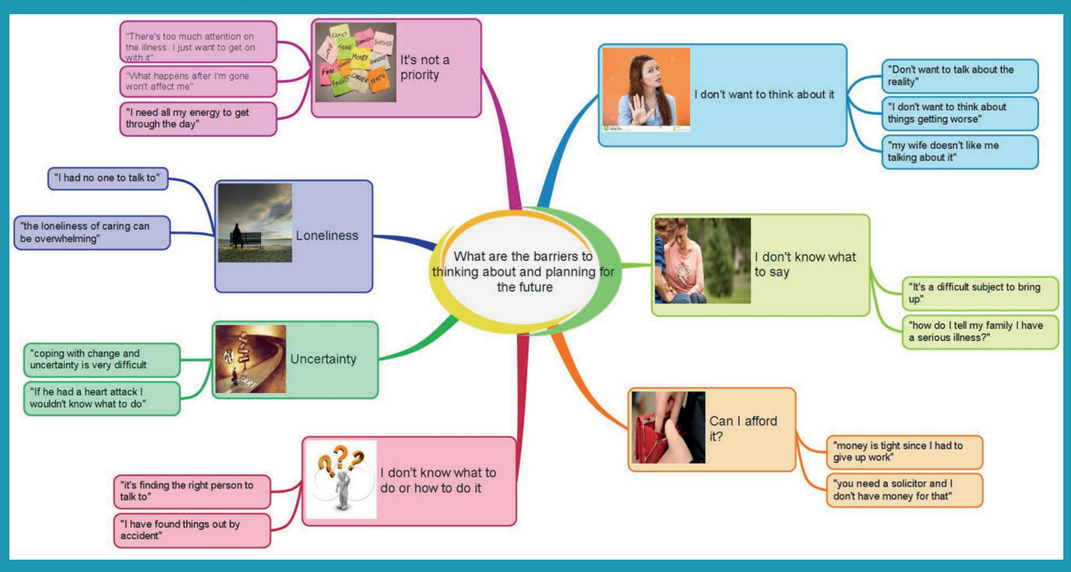
Direct quotes from each session were analysed thematically using Framework analysis. The findings were verified at two further engagement events.

Findings

What matters to people as their health declines:



Barriers to thinking ahead and planning for the future were:



Conclusion

We have found that

- Some people want to make plans for the future, but for others this is not a priority.
- People need information to help them to plan ahead which is relevant to their local situation and personal circumstances.
- People need information and support to initiate difficult conversations with professionals and loved ones.

From the engagement sessions we identified that information is key to enabling and supporting people to make plans for end of life.

We worked together with people with LTCs in two local communities to find and look at information which might help them. People from these groups have since delivered pop up information stations in their local communities. A rolling programme has now been set up for delivering this in a variety of community venues.

References

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