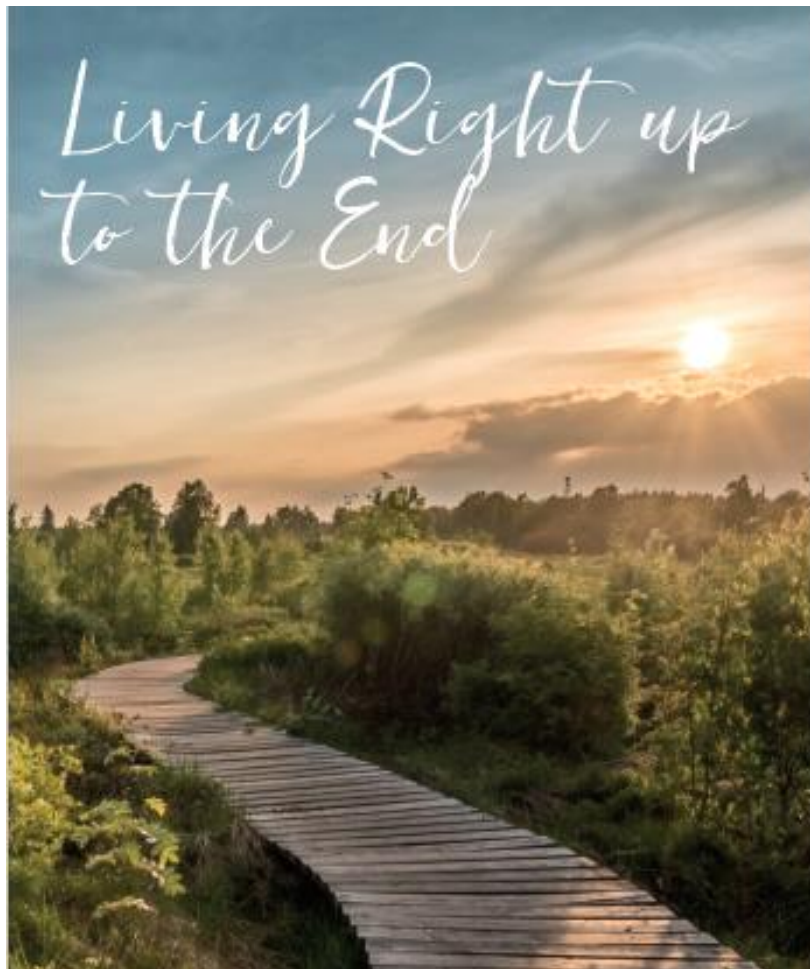




## **LIVING RIGHT UP TO THE END - STRATHCARRON HOSPICE**

### **Final Report**

**Susan High, Sally Boa & Marjory MacKay**



## **BACKGROUND**

This final report has been co-produced by the project team and two participation groups consisting of individuals living with long term conditions (LTCs) as well as present and past carers. This report describes a project which grew beyond the expectations of the original bid. It enabled us to develop an understanding of the support people living with LTCs and their carers want when facing the challenge of deteriorating health. It also enabled us to break down some of the barriers associated with talking about palliative and end of life care and death and dying.

## **THE PROJECT**

We set out to find out what people with LTCs need and want in relation to support to enable them to self-manage whilst living with declining and unpredictable health towards the end of life. Specifically, we wanted to:

- Find out how people with LTCs self-manage their lives and maintain control through a range of challenges that they and their families face in the last year of life.
- Enable more individuals with LTCs and their unpaid carers to engage with, think through and plan ahead for the end of their lives.

In order to do this we worked with two communities in the area that we serve; Denny and Alloa/Hillfoots.

The project was in 3 phases:

### **A. *Community asset mapping***

We worked with local community groups, people with LTCs and their unpaid carers to find out:

- a. What resources were available for people living with LTCs as they approach their last year of life
- b. Who used these resources and how were they run
- c. If there were any gaps in services/resources
- d. Who were the key players who made things happen in these local communities

### **B. *Community engagement***

We ran a series of community events ('think tanks') where existing community groups (such as over 50s group, lunch clubs, Braveheart, Equal People) were invited to discuss their views and experiences about what mattered to them in relation to community support to enable them to live actively with deteriorating health.

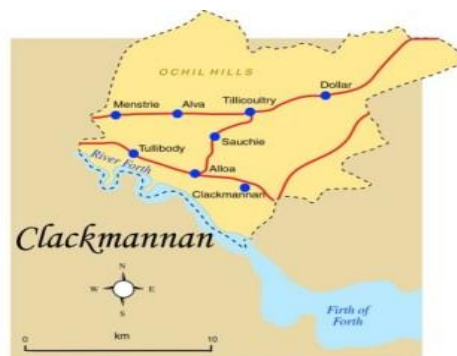
### **C. *Co-design of services***

Having gathered the views of a range of people living with LTCs, we worked with them to design a menu of options to empower them to manage their own health, to live whilst dying and plan ahead.

## **A. Community Asset Mapping**

We researched asset mapping and asset mapping toolkits. Initially we experienced difficulty recruiting to focus groups. As a result it was not possible to use the ALISS asset mapping toolkit method which suggests organising workshops with groups of people as a starting point. Instead we adapted ideas from a toolkit available from “Brighter Futures Together” (an internet resource of “information and ideas to help you grow and improve your community” provided by a partnership of agencies in the north east of England).

We used a variety of methods from this toolkit to identify resources available in each project area. We found out where and when they met, who the key contact person was, and what their target group consisted of. Across both areas we found groups which provided social activity and support. We identified a gap in provision of social support for men. We also identified only one group in each area which was specifically targeted at supporting people with LTCs.



In **Clackmannanshire** we initially identified 66 groups. These groups provided a combination of social support, activities, information and advice. Only one group was specifically aimed at people with Long Term Conditions (Breatheasy). The other groups had a variety of target audiences e.g. Men’s Shed, Women’s Guild, Nifty Fifties, Craft2Distract, Knitting group. We included groups which were based outside the area but offered support or information to people within the area, for example Solicitors for Older People Scotland, Alzheimer’s Scotland.

We applied exclusion criteria to the asset map which reduced the number to 35 groups which all had some relevance to long term conditions, had a local meeting point, and had an identified contact person. These 35 groups became the target for recruitment to the community engagement process.

Examples of groups in this cohort include:

- ❖ Carers support group
- ❖ Circle of Friends
- ❖ Tullibody Healthy Living
- ❖ Singing for Memories
- ❖ Action in Mind



The **Denny** project area consisted of Denny town and the surrounding villages of Dunipace, Dennyloanhead, Longcroft, and Banknock. In this area we found 47 groups including Knit and natter, Home Start, Wednesday Welcome. These groups provided social support to various target groups including people with LTCs and their carers. Only one group was aimed specifically at people with LTCs (Stroke Group). We applied the same exclusion criteria which resulted in 25 groups to target for community engagement. Targeted groups included:

- ❖ Stroke Group
- ❖ Nifty Fifties
- ❖ Parish Church Women's Group
- ❖ Carer's support group

We approached all 60 groups (35 in Clacks and 25 in Denny area) to invite them to participate in an engagement session. Eighteen groups agreed to take part.

### **Asset Mapping in Action – Making Connections**

One group which agreed to an engagement event was the Banknock Nifty Fifties. This is a group of 35 – 40, mostly women, who meet weekly throughout the year. A large number of the group are living with a long term condition or are caring for someone who was. The group provides social activities, and practical and emotional support. They pride themselves on welcoming new members and supporting members who are experiencing health or other difficulties.

The engagement event started with an update on Hospice services at their request. As Banknock is local to the hospice, many had personal experience of the services. They were however very surprised at the range of services offered and that it was “so much more than a place to die”.

We asked the group three questions:

- ❖ What would be important to you if you were living with a long term condition and your health was declining?
- ❖ What are the barriers to you and your loved ones thinking about and making plans for the future?
- ❖ Do you have any suggestions of how we could work together to help your community to support people to live actively with declining health and to make plans for the future?

The group found it difficult to talk about these issues, with many avoiding using words such as 'death' or 'bereaved'.

"I want my family to know what I want so it's easier for them when....."

"I would want company so I could take my mind off.....things"

"The family don't like me talking

"It's a difficult subject to talk about"

"I know I need to make a will.....It's just.....it's not rational but you feel like it makes it more likely to happen"

"Thinking about it makes you feel vulnerable ..... it's all doom and gloom"

This engagement session is one example of how we used the asset map to make connections, begin to break down some of the barriers of talking about death and dying and work towards the next phase of the project. The process of asset mapping as a whole enabled us to engage with key players in each community and make connections with groups who were interested in working with us. This was an iterative process which built as we made relationships with people.

## **B. Community Engagement**

We held 18 engagement events with groups identified from the asset mapping exercise. These events were held at the usual meeting place of the group. Each event was planned around the usual routine and the requirements of that particular group, but each group were asked to consider the same three questions as tested during the asset mapping phase of the project (see page 4).

We collected direct quotes and post it note responses to questions one and two, and used Framework Analysis to identify themes. We produced mind maps to represent the findings from the first two questions (Appendix 1). The responses to question three were general in nature and people found it hard to come up with tangible suggestions. People told us they wanted information but did not say what type, or how or where they would prefer to access it.

We invited people from all 18 engagement events to attend a follow up event which served two purposes:

1. To validate the findings represented on the mind maps
2. To identify potential solutions which might support people to overcome the barriers which stop them from planning ahead

At this phase two event the groups validated the findings as being accurate. The participants felt that access to information was an important and common thread which ran through the response themes to both question one and two, and felt this should be targeted as a potential solution for helping people plan ahead.



We invited participants in each of the project areas to form a working group to explore the issues around information in greater detail and to co-design an intervention to address these. We held meetings in local venues monthly over a four month period. These meetings were attended by a core group of ten people in each area. Attendance at meetings varied from four to ten people who either lived with LTCs or cared for someone who did. Each meeting is summarised below.

#### **Meeting 1**

The group talked about different types of information and what might or might not support them to plan ahead.

#### **Findings**

People felt they had been given information at the wrong time for them. They said that information about planning for the future provided at time of diagnosis was rarely used.

- People wanted to have control over the type of information they access, where they access it, and when.
- People felt they needed different types of information, especially around emotionally sensitive subjects. Some people like a very direct approach “something like a to do list, that just tells me exactly what I need to do”. Others preferred a softer approach “I want my plan to be about living, with end of life as one part of that”.
- People felt that having someone to chat to about the information available would be useful.
- The group decided that an information stand as a “pop up” in a public space manned by trained volunteers should be developed and tested.

The group reviewed a wide range of available information and identified the resources which they felt were readable and usable.

- The group felt that for the purposes of the information stand the resources should be restricted to two topics – planning for the future and having difficult conversations.
- Some participants felt the newly launched national ACP tool was useful. Others felt it to be too clinical. A range of planning tools was chosen to reflect individual needs and preferences, including the new ACP tool.
- Some resources are available to download only e.g. Office of the Public Guardian. These resources were printed or requested in hard copy.
- 15 participants volunteered to staff the information pop ups and agreed to attend a training session to familiarise themselves with the resources to be used.
- A full list of resources is provided (Appendix 2)

The group were asked to find resources on the internet and came back to discuss their experience.

- Only two group members participated in this exercise. Reasons for not participating were; no access to computer, no access to printer, felt uncomfortable or anxious about finding something which might be frightening, limited searching skills.
- Those who did participate used vague search terms and returned large numbers of results. This felt overwhelming and they were unable to pick out the reliable information.
- There was a consensus that hard copy information is preferable.

Participants evaluated their experience of being involved in the project. We used emotional touchpoints to find out how they felt

- **On first hearing about the project** they felt interested, curious, included, hopeful. One participant felt cynical, having been involved in consultation before where she felt her involvement was “a box ticking exercise”
- **On being asked to think about and talk openly about death and planning for end of life** they felt scared, anxious, upset, worried. They also felt safe, supported, respected, looked after, calm.
- **On the overall experience of involvement in the project** they felt:





During the engagement and participation events, a group dynamic emerged which supported open discussion about end of life, death and dying. People shared experiences and developed a sense of “common purpose” as they came to appreciate the positive impact of openly discussing difficult and taboo issues. They became motivated to encourage others – friends, family, and neighbours – to think and talk about difficult issues as they had done. They identified in themselves a change of attitude, which led to a change in their behaviour, which included being able to talk more openly about death and dying.

### **C. Co-design of Service**

By the end of the engagement and participation events, the groups had identified what type of information should be included in a pop up stand to be tested in three locations.

Planning for the information stands involved:

- ❖ Recruiting volunteers.
  - We recruited a bank of 29 volunteers willing to staff the information stands. Nine were current Hospice befrienders, six were Hospice volunteers in other roles, 15 were participants from the engagement process.
- ❖ Training volunteers
  - We held a half day training session to familiarise the volunteers with the materials and to provide training in listening and responding appropriately.
  - We emphasised during this session that the volunteers should listen and signpost but not give advice or attempt to “fix things”.
- ❖ Venues
  - The participants felt that health centres were the natural location for the stand. We obtained permission to set up the stand in one large health hub in Alloa, and in a GP practice in Denny.
  - The project team felt that it would be useful to compare these health settings with a more general public location. Following discussion with the volunteers it was agreed to hold a pop up in a large busy supermarket in Alloa.
- ❖ Design
  - Together with the volunteers we designed a pop up banner and table cover for the stand
  - The agreed information resources were sourced by a combination of purchasing, downloading and requesting from organisations.



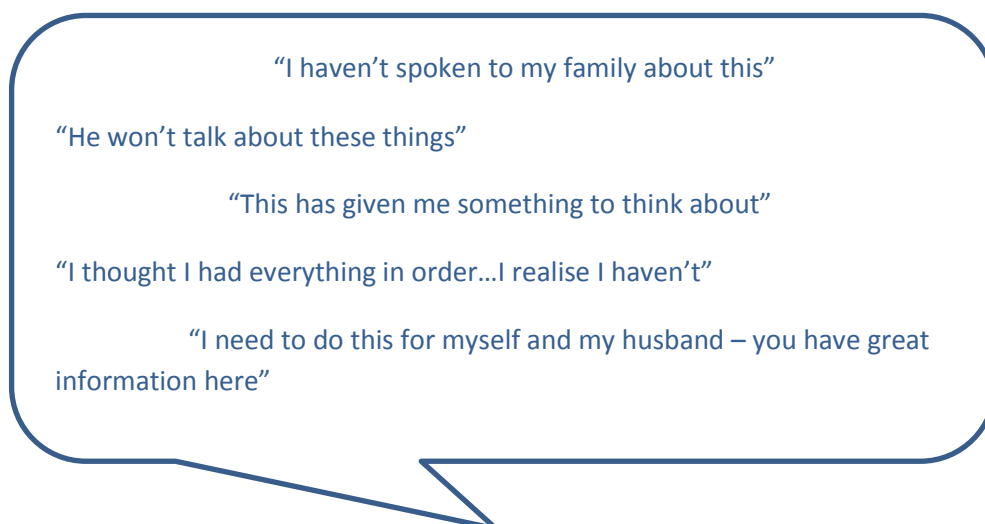


## Findings:

A total of 80 people (52 female, 28 male) accessed the stand across three venues.



## Comments included



## What we learned about the information stands

The information stand looked attractive, but in all venues there were a number of people who thought we were fundraising for the hospice. People did not approach the stand without being approached by the volunteers. It took some time for the volunteers to work out the best way to make this approach. The volunteers grew in confidence over time and were empathic and genuine. People approaching the stand talked to the volunteers who showed them relevant information. Thirty eight people engaged and took leaflets. Twenty four had specific information needs. Fourteen had general interest and took a range of information. Two health professionals took multiple resources which they felt would be useful in their practice. They had been unaware of the range of information available.

The most popular leaflets were those produced by Solicitors for Older People Scotland (Must dos for the over 50s, Handy Guide for Older People), and AgeUK Lifebook (a tool for collecting useful life information which also has a planning ahead section). The most successful stand was in the foyer of a large health hub where people attended for a variety of health related purposes. It proved difficult

to engage with people at the supermarket. There were requests for information in different languages, and in formats suitable for those with learning difficulties and visual impairment.

More specific training is needed to support volunteers who are staffing the information stands. For example, some needed suggestions about appropriate phrases to use to initially engage with the public about the main purpose of the stand. Each volunteer needed clarity in relation to their role and it was felt that it was important to have discussion and preparation before the stand opened – introducing each other, planning roles. A debrief at the end was felt to be helpful to clarify what went well and what they would change next time.

### **Reflections on “Living Right up to the End” project**

During this project we, as a hospice, have set out to work with people with LTCs and their carers to find out what is important to them as they live with declining health. For many the subject matter has been difficult to think about. It has been clear that the subject of death and dying is still very much taboo in our society. This made the beginning of the project difficult, and we had to find creative ways to help people to overcome the barriers of fear and discomfort.

We found that face to face contact was effective in reducing anxiety and reassuring people that although these subjects were difficult to think and talk about, the sessions would be handled sensitively and with respect. When people felt safe they committed to the project and shared some very personal stories. Five individuals from the initial preparatory focus group have been involved at every stage of the engagement and are now volunteering to provide a personal presence at the pop up stands.

One participant’s story illustrates her personal journey:

#### **Margaret’s Story**

Margaret attended the initial focus group, clearly apprehensive about meeting “people from the hospice”. She felt “uncomfortable” about talking about end of life and had not made any plans for her future although she had a deteriorating health condition.

Over the duration of the project she noticeably relaxed and contributed more of her own story, and her thoughts about what mattered to her. She became a valuable member of the group, always aware and empathic if another participant was finding the subject matter difficult.

She participated in all of the activities, including searching the internet and testing out the newly launched national ACP document. She found this document so useful that she asked if I could get a copy for her and her husband to complete and keep.

Over the duration of the project she became increasingly comfortable with conversations about end of life and making plans. She started asking friends and neighbours if they had ever given the subject any consideration. She became an ambassador for planning for the future, providing friends and family with information and resources to suit their individual needs.

At the final session she said she had felt listened to, respected and valued. She told us “I was always told I was stupid, then I became DISABLED and stupid! I didn’t think I had anything to offer. I have been able to do this. I have made new friends. I have made all my plans and spoken to my husband. I want to thank you”

### **What has changed as a result of this project?**

We have identified what is important to people as they approach end of life and have found that several barriers exist which stop people thinking about and making plans for the future. These include having access to the right information in the right format at the right time. People also struggle to open up conversations with family and friends because death and dying are still very much taboo subjects within Scottish society.

Over the course of the project, we produced asset maps for each of the project areas and now have a much greater understanding of the supports available for people living with LTCs in their local communities. As a result of this, **we now have meaningful connections with individuals and groups in the two areas where we have been working.** This has led to a much greater understanding of each other's roles, needs and what we can each provide. We have raised awareness in the project areas of the hospice and the wide range of services it provides. By giving the hospice "a face" we have reduced the fear and corrected some misconceptions. We have also developed an understanding of the resources already available in each community and have a better appreciation of what might help or hinder people from planning ahead when faced with life limiting illness.

We have **co-produced an information resource to meet a range of personal preferences around making plans for the future and having difficult conversations.** We plan to continue to provide pop up information stands in local venues. We have stands booked for Older People's forums arranged by the third sector interfaces in both project areas.

We found that the newly launched national Anticipatory Care Planning document was felt to be useful by some people, but others found it too clinical and did not like the format. We sourced a variety of planning tools thereby providing people with a choice. One of the most popular resources was a Lifebook produced by AgeUK. The engagement groups liked that this book was **"a plan for living, which includes a plan for the end of life."** They also liked the section on funeral planning. They liked to have all of their important information in one place. It has proved difficult to acquire copies of this resource in sufficient numbers. **We have now designed a local version of this and it is available to people in the local area.**

We have **grown a group of people who now act as 'ambassadors' in their local communities.** They actively promote the importance of talking openly about death, dying and bereavement, and the value of making plans for the future. These citizens have embraced the concept of providing people with information in community venues and are keen to "get on with it" by actively finding new venues to take the stand to. They no longer feel they need a professional to be present at the venues and have suggested that we as a hospice can act as a support from a distance. They have suggested we meet regularly to discuss their feedback and make adjustments to the materials provided and to the training as required. This model can be used for further developments across the area.

We have **raised awareness of the importance of 'putting people in the driving seat' of their health and well-being, including making choices and decisions about their deteriorating health.** We have shared the learning from this project at local and national meetings and conferences. Through working together with people who have LTCs, we have heard their voice and they have shaped our thinking as we plan for the future.

## **Next Steps**

The learning from this project has changed the thinking of Strathcarron Hospice Community Development. We have learned that there are many assets within communities which could support people living with LTCs. This has challenged our thinking and presented opportunities to review other services provided by the hospice. In the future we plan to recruit volunteers in each village or locality served by the hospice who will be a “virtual asset map” for their local area. This resource can be used by our community clinical nurse specialists and our day services to provide people with other sources of support to augment the specialist services they receive from Strathcarron.

We have had a volunteer befriending service at Strathcarron for a number of years. We now realise that there are other roles for volunteers in their local communities. As a result of our learning we have been successful in securing funding from the Falkirk Integrated Care Fund to explore the “Circles of Support” model. We intend to train volunteers to work with individuals and their carers to identify what support they have, to identify gaps, and to help them find their own community solutions.

We have found that volunteers want to talk to people about difficult issues around end of life planning. We aim to provide a training programme for volunteers so they can offer support to people who need help to make plans for the future and to communicate these plans to their families. We plan to recruit many new volunteers to provide these services, and to call the new service “Strathcarron Community Support Volunteers”. The support provided will be individually tailored to the person’s needs.

In the words of one participant:

“I feel we’ve done something good, I admit I was sceptical - people are always asking for opinions but nothing comes of it. This has felt different. But we’re not there yet. Success will be when we have these information points popping up regularly in the community and people know that is the place to go to have a chat and find out about making plans. And then if they actually do it... that will be something!”

## **Acknowledgements:**

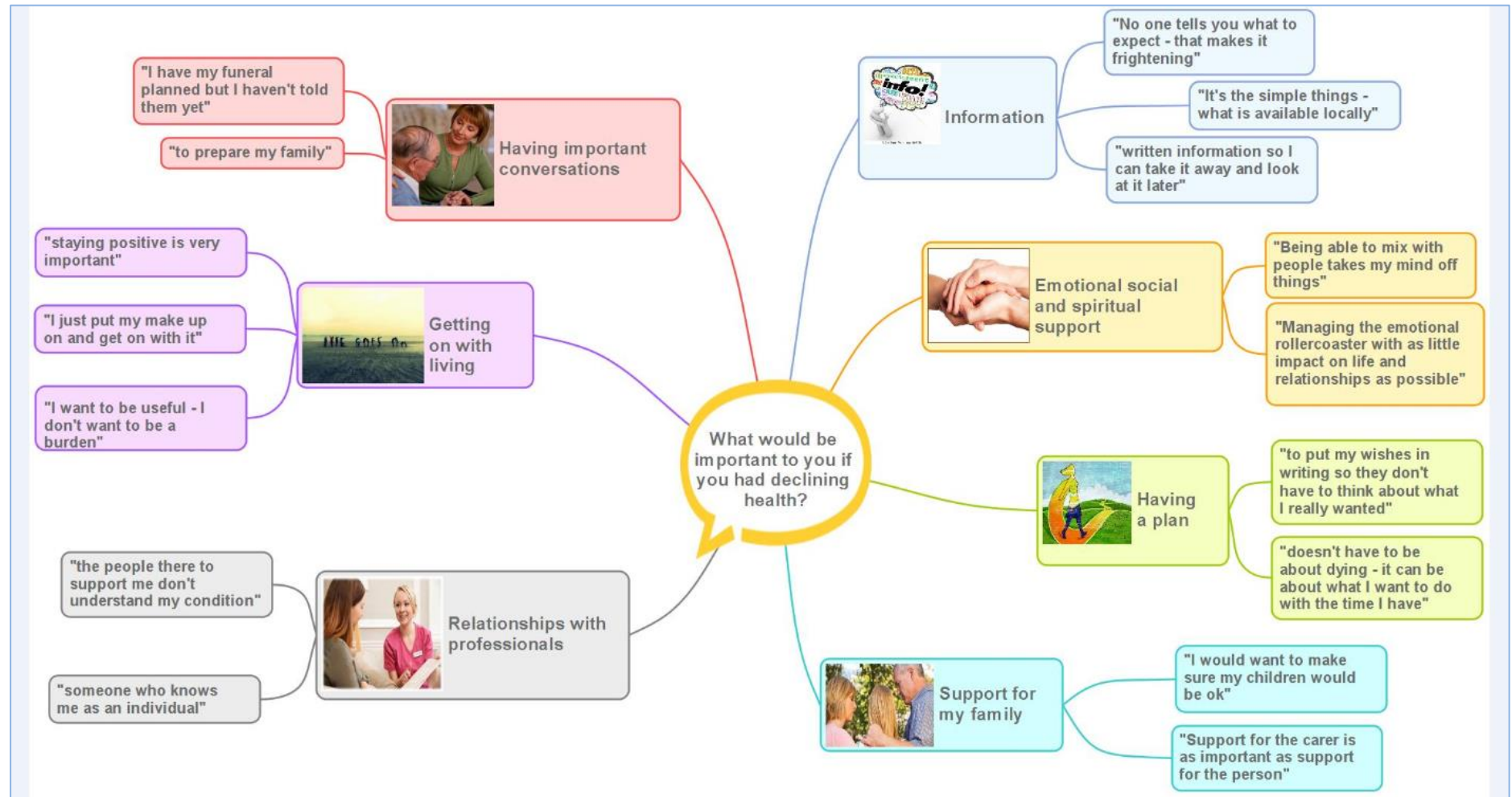
This project was funded by the Health and Social Care Alliance Scotland. We are very grateful to the people of Clackmannanshire and Denny who willingly and enthusiastically gave up their time to participate in the project. We would also like to thank Play Alloa and Denny library for the use of their facilities and the catering staff at Strathcarron for providing homemade goodies which oiled the wheels of discussions. We are also grateful to the project steering group for keeping us on track, and would particularly like to thank Catharine Mackinlay who shared her wisdom about community development and gently steered us in the right direction.

**Contact details:**

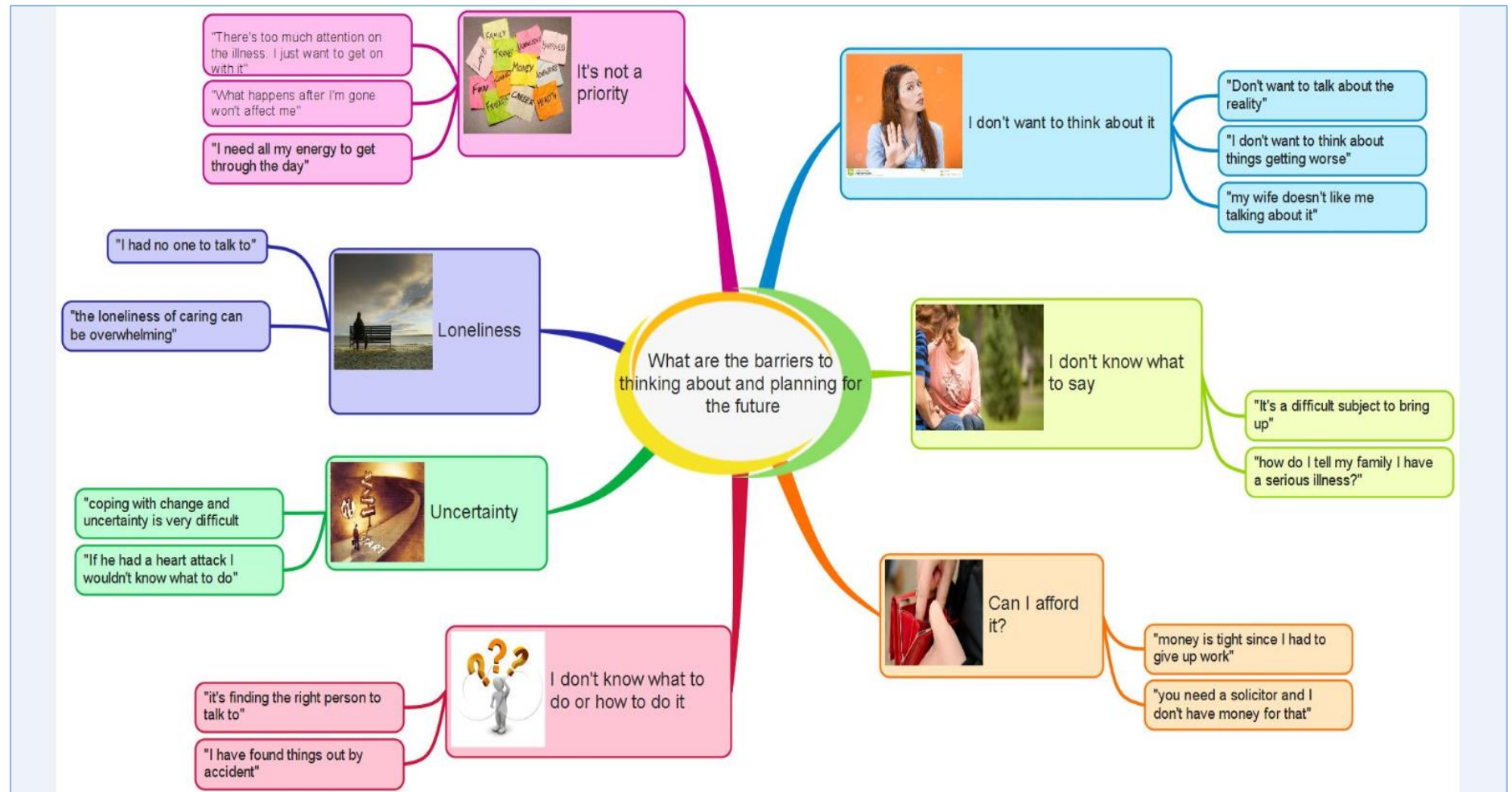
If you would like further information about the project, please contact [susan.high@nhs.net](mailto:susan.high@nhs.net)

## Appendix 1

What is important?



## What are the barriers to planning ahead?





## **Appendix 2**

### **Information Stand Resources**

- Anticipatory Care Plans
- Dying Matters “Putting your house in order”
- Dying Matters “Remember when we...”
- Dying Matters “My Funeral Wishes”
- NHS Forth Valley ALFY (Advice Line for You) information leaflet
- Strathcarron “Planning your Future”
- Useful websites sheet
- AgeUK Lifebook
- Dying Matters “Talking to Children about dying”
- Dying Matters “To do list”
- SOPS (Solicitors for Older People Scotland) Handy guide for older people
- Dying Matters “5 things to do before I die”
- NHSFV Thinking ahead
- NHS Improving Quality” Planning your future care”
- Later Life Information Centre contact details
- SOPS “Do the right thing”
- Office of the Public Guardian “What is a Power of Attorney”
- AgeUK “Before you go”
- Dying Matters “Thinking of you”
- Good Life Good Death Good Grief Thinking about the future origami game