THINK TALK ACT

An initiative from Pilgrims Hospices

THINK SESSIONS

POST PILOT REPORT

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Executive Summary

It is known from a demographic perspective that 1% of the population will die each year, which in the area Pilgrims Hospices' serves equates to approximately 7500 people and approximately 2500 of these people are supported by the hospice.

Many of these patients and their families may not yet require intensive support services but they could benefit hugely from raising awareness about future planning of their care and wishes at the end of life and enabled access to other support offered. Currently families are usually referred to our hospice service in the last 10 weeks of life. Evidence suggests this late referral is the same in other hospice settings, particularly for patients with non-cancer conditions and older age groups. This often presents as a crisis management scenario rather than an advance plan of care with early support for patients.

To look to address this Pilgrims Hospices are rolling out a project known as THINK, TALK, ACT, which will enable GP Practices to identify and support relevant patients, and introduce proactive personalised care planning for everyone identified as being at risk of being in their last year of life. This will enable more people to be made aware of their situation at an earlier stage so they have the mental and physical capacity to take time to 'Think' through what they would like to happen and put plans in place. This report outlines the findings from a pilot evaluation of the 'Think' part of the project.

We collaborated with two GP surgeries in the East Kent area to run the 'Think' pilot. A cohort of their patients identified through a screening tool as moderately frail were invited through their GP practice via co-designed letter to attend a 'Think' information session. Invites were sent to 1050 households in the two participating surgeries. 8.38% (88) of invited patients attended along with their 67 guests giving us the overall total of 155. They attended one of 11 'Think' sessions run by Hospice Facilitators.

The aim of the pilot was to understand how the 'Think' programme was working to refine the future roll out of the programme and evaluation methods. Surveys with attenders/non-attenders, semi-structured interviews with attendees and GP practice staff, documentary analysis of the reflections of session facilitators were used to evaluate the 'Think' pilot.

All 'Think' attendees who completed the evaluation form (n=102), indicated that the session was informative, the facilitators were helpful, and they would recommend the session to others, and should be available to more people. Some expressed that they appreciated having the one-to-one time with the facilitators after the presentation. Others suggested that they would like further support to help put what they had learnt into action e.g. to write their plans, navigating conversations with their GP and families.

Three attendees who took part in depth interviews elaborated further on the value and importance of the session, and the usefulness of the materials that had been given at the session. Following the session they had used the information to help plan their (or their loved ones) wishes or intended to use them in the future to do so. These attendees had already put a lot in place, particularly in terms of lasting power of attorney and making a Will, but less around the area of their future care and treatment. The session gave them a sense of reassurance that what they had done so far was correct but there was more that they needed to consider, and the session had started to give them the information to start doing so.

One hundred and fifty people who declined to attend a 'Think' session returned a questionnaire to provide further information on their reasons for not taking up the offer of a 'Think' session. Over half of these participants (52.7 %) advised that they had no interest in attending our events. Further analysis of the comments received, just over half (38/75) indicated that there was lack of understanding that this session was preparing for their future. Similar themes were also felt by attendees also, who were not sure quite what to expect, and thought that the purpose of the session could have been clearer in the invitation.

Attenders/non-attenders and feedback from the GP staff indicated that the invitation letter could be improved so it was clearer as to why patients had been selected and explain that the session did not mean that they now required hospice care, and removing terms that were difficult for people to understand i.e. 'complex medical needs'. These changes were put in place in a revised letter for further mail outs in the pilot, and an improvement was seen.

Further recommendations were made for how the letter and the processes and procedures could be adapted further to improve uptake in future roll out of 'Think', e.g. letter addressed from the surgery rather than the hospice, location of sessions at the surgery or community venue rather than the hospice, explore advertising options so people become aware of the programme.

The screening tool (electronic frailty index) worked well for identifying patients that were valid (appropriate). However further guidance was felt to be needed for a future roll out in terms of the screening criteria for selection of patients from the GP surgery caseload. Large numbers of patients were identified, more than could be handled in one or two mailings and the available 'Think' sessions. Guidance for GP reception staff was also developed to help them field and handle calls relating to 'Think' which had positive feedback. In addition it was felt that any person taking on a dedicated role to handle calls and session bookings in the future should have advanced communication training to be able to deal with calls that may be difficult or challenging.

The hospice staff facilitating the 'Think' sessions reflected that during the pilot they were able to refine the presentation and make improvements to the content and flow. The one-to-one time with attendee was observed as being very beneficial to aid discussion. A useful addition to develop from the experience of the pilot would be a FAQ list to provide as an additional resource to future facilitators and attendees.

The facilitators reflected that future sessions could be run by a hospice wellbeing practitioner role if trained with competencies. A minimum of two facilitators would be required with a maximum of 25 attendees. The average number of attendees was 14, which was seen as a good size group. Small groups (less than 10) did not work as well for the facilitators. Provision of some of the material upfront or in alternative formats were also suggested by attendees and practical issues had to be considered and prepared e.g. access to buildings out of normal hours or for visually or physically impaired attendees.

Overall, the 'Think' programme and it's evaluation method are recommended for further roll out with some minor amendments. The programme was seen as successful, of benefit to attendees, and acceptable with same amendments by the GP surgery and hospice staff involved. A larger evaluation of the roll out of the programme to other areas and over a longer time to follow up patients would be recommended to understand if the 'Think' programme as a positive effect on patient outcomes relating to advance care planning and end of life care.

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Introduction

It is known from a demographic perspective that 1% of the population will die each year, which in the area we serve equates to approximately 7500 people and Pilgrims support approximately 2500 of these people.

Many of these patients and their families may not yet require intensive support services but they could benefit hugely from raising awareness about future planning of their care and wishes at the end of life and enabled access to other support offered, such as sessions provided by the hospice therapy centres. There is also likely to be unmet need amongst this group for the expert services the hospice provides.

Pilgrims Hospices are rolling out a project known as THINK, TALK, ACT, which will enable GP Practices to identify and support relevant patients, and introduce proactive personalised care planning for everyone identified as being at risk of being in their last year of life. This will enable more people to be made aware of their situation at an earlier stage so they have the mental and physical capacity to take time to 'Think' through what they would like to happen and put plans in place. This initiative will also be an important link into the Single Point of Access programme ensuring these earlier identified group of people have the right access at the right time.

This report outlines the findings from a pilot evaluation of the 'Think' part of the project.

Rationale for 'Think Talk Act'

Pilgrims Hospices in east Kent plays a significant role in the support and care of patients and families facing the challenges of terminal illness; especially in the last year of life.

There is a growing body of evidence to support the need for 'earlier recognition and referral' for patients and their families to receive palliative care (GMC 2010) and that early support leads to better outcomes at the end of life, including less emergency admissions into hospital (Qureshi et al 2019).

Currently families are usually referred to our hospice service in the last 10 weeks of life and this referral is mostly generated by the hospital oncology teams. Evidence suggests this late referral is the same in other hospice settings, particularly for patients with non-cancer conditions and older age groups (Allsop et al 2018). This often presents as a crisis management scenario rather than an advance plan of care with early support for patients. This therefore limits the hospices' ability to be equitable and effective in offering support to as many people as possible when it could be most beneficial (Murray et al 2017).

There is nothing new in GPs being tasked to produce lists of patients with different health challenges but it is the 'so what happens next' that the THINK TALK ACT programme is designed to support.
The 'Think' sessions are not designed to replace the patient/doctor consultation but to allow the GP to prescribe a social intervention. We believe our proposal will save GPs time in identifying the right patients plus enabling more efficiency by working along-side them to create cost effective and timely plans that meet the individual's needs, via the 'Talk' element of the intervention. This new service will also support GP's to meet their contractual obligations for End of Life management as outlined in the January 2019 NHS England GP Contract and will be a vital link to the new Single Point of Access service.

What is the 'Think' programme?

'Think' is concerned with engagement of the population identified as moderately frail, to be identified by the electronic frailty index (eFI) https://www.england.nhs.uk/ourwork/clinical-policy/older-people/frailty/efi/. The eFI is a validated model for identifying and categorising mild, moderate and severe levels of frailty of patients using GP records (Clegg et al 2016) and is available as part of toolkit for GP practices to use to support people living with frailty (NHS England 2017). Patients with frailty are shown to be at greater risk of hospital admission and have low rates of advance care planning in place (Hopkins et al 2020). This cohort would be invited through their GP practice via co-designed letter to attend an information session at their GP Surgery or other local community space . These sessions would be delivered by our specially trained Pilgrims Wellbeing team who will provide information on how to make plans for the end of life e.g. decisions about clinical interventions such as resuscitation or unscheduled hospital admission, Lasting Power of Attorney and capturing other wishes. There will also be take away literature given to attendees to encourage 'putting things on paper' and to encourage discussions with family members.

The 'Think' pilot

We collaborated with two GP surgeries in East Kent to run the 'Think' pilot, referred to as Surgery A and Surgery B in this report. They used the eFI to run lists on their patient records in February 2022. An invitation letter was then sent to the identified patients from the surgery. For the pilot, sessions where held at a Pilgrims Hospice Therapy centre (pictured below) and facilitated by existing hospice staff (a nurse, social worker and occupational therapist). The pilot was supported by the hospice business manager who was a point of liaison with the surgeries and organised and set up the sessions. They were also the point of contact for invited patients to book onto a Think session or if they had any queries.

Our THINK pilot events ran from 24/2/2022 to 3/5/2022

During that period we held **11** 'Think' sessions and sent invites to **1050** households of our two participating surgeries.

These invites were sent to a cohort of patients coded as moderately frail within their surgery:

'Moderate Frailty: Needs help with all outside activities and with keeping house. Inside problems with stairs, needs help with bathing and may need minimal assistance (standby) with dressing'

Surgery A

Surgery A has a population size of **24,790.** of this **1.45%** were identified as moderately frail = **359 patients**

Of the moderately frail patients we invited **9.47%** (34) attended an event along with their **27** invited guests, giving us the overall total of **61.**

Surgery B

Surgery B has a population size of **17,602.** of this **3.92%** were identified as Moderately Frail = **691 patients**

Of these moderately frail patients we invited, **7.81%** (54) attended an event along with their **39** invited guests, giving us the overall total of **93**.

Summary of attendees

We had **8.38%** (88) moderately frail patients attend our events from the two surgeries along with their **66** invited guests giving us the overall total of **154**.

session no.	Date attended	No. of attendees
1	24/02/2022	14
2	08/03/2022	14
3	12/03/2022	17
4	15/03/2022	14
5	22/03/2022	19
6	22/03/2022	8
7	26/03/2022	14
8	19/04/2022	17
9	28/04/2022	22
10	28/04/2022	6
11	03/05/2022	9

We also had **24** guests book and cancel or did not attend on the day, of these, a further 6 rebooked and successfully attended, ***if the 18 that had cancelled, if they had attended, our patient attendance rate would have been 10.09% plus their guests.***

Male vs Female

We had 45.45% (40) Male patients attend

We had 54.54% (48) Female patients attend

Most and least popular days/times

Our events were made available on a variety of days and times during the pilot

Tuesday 3.30-5pm was our most popular request

Any day 6-7pm was our least popular uptake

We held 2 events on a Saturday

Pilot Evaluation

Aims:

1. To understand how the 'Think' programme worked in a small number of GP pilot sites and refine for future roll out.
2. To understand how the evaluation methods work to inform a future evaluation of the roll out of 'Think'.

Objectives:

(to meet aim 1)

- Assess the take up of 'Think' sessions. Whether people are willing to engage having been identified and sent an invitation. Who attends.
- Assess patient acceptability, views and experiences of the programme: Their evaluation of being approached for and attending the 'Think' session and its usefulness. What actions attendees take (or intend to take) as a result of the session. e.g. advance care plan discussions with GP or family/friends.
- Assess facilitator acceptability, views and experiences of organising and running the THINK sessions.
- Assess GP practice staff acceptability, views and experiences of the 'Think' intervention.
- Assess the resource required to deliver the service when up-scaled.

(to meet aim 2)

- Assess the methods used in the evaluation: what worked and what may need to change or be added based on the findings from the pilot.

Methodology:

Firstly, a short questionnaire was used to gather information from patients on why they did not take up the offer of a 'Think' session which was sent out with the letter of invitation with a pre-paid envelope to send back the hospice.

The views of the session for those who attended were collected by an short evaluation form at the end of the session.

Qualitative methods were used to understand in more depth what the participants thought of 'Think' and to see what impact the session had made since, by finding out what actions participants and taken or planned to take. This was by telephone /video call interview, of a sample of attendees who completed a 'consent to contact' form to be approached to be invited for interview, approximately 3-6 weeks after they attended the session. It was not anticipated that participants will have necessarily acted upon the advice after this time and a longer follow up would be advantageous. However, due to timescales for planning for further intervention roll out a longer time frame for follow up was not practical for this pilot stage.

The pilot GP surgeries were also asked about their acceptability, views and experiences of the 'Think' programme (the process of identifying and inviting patients) using qualitative methods. Practice staff directly involved in the 'Think' pilot were invited to take part in an interview.

An adapted 'action research' approach to evaluation of the 'Think' session facilitators and programme manager was adopted to understand their acceptability of the intervention, and how they continue to develop the programme following their reflections. This approach has been used for evaluation in palliative care, including with ACP peer educators (Froggatt and Hockley 2011). Pilgrims Hospice staff involved in the development and delivery of the 'Think' intervention (e.g. 'Think' session Facilitators and Programme Manager)were invited to complete a reflective practice template (individually or as a group) after each session for their reflections and then take action as needed for the next set of sessions. The template used is developed by the Health and Care profession council: https://www.hcpc-uk.org/globalassets/standards/meeting-our-standards/reflective-practice/templates/reflective-practice-template.pdf

This template was adapted with prompts to reflect the specific aspects of the programme. A documentary analysis was performed on the completed templates.

Informed consent was sought from all the GP staff and 'Think' attendee interview participants, through a participant information sheet and consent form. Consent was received by wet link completion or electronically. Consent was assumed for those completing and sending back completing evaluation forms and reflective templates.

During 2018 and 2019 The 'Think' programme was developed with advice and support through hospice staff led sessions . These sessions reviewed the concept of the 'Think' programme and all associated materials including the 'Think' booklet, banners, invite letter and evaluation form and were used to further discuss formulation of the session content and presentation. Pilgrims Hospice Volunteer focus groups were also arranged for review of these materials and to have the opportunity to put forward further ideas and suggestions.

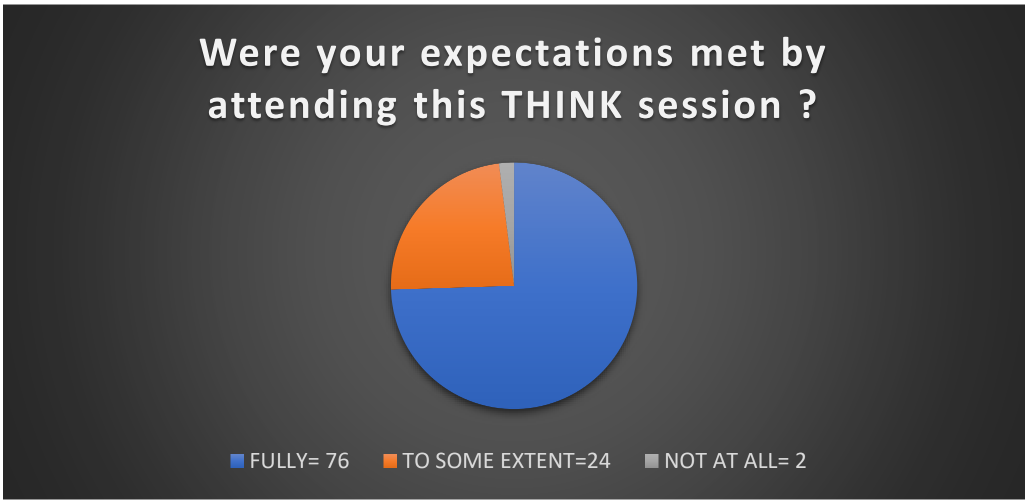
We also approached a Clinical Commissioning Group in east Kent for their comment on the invite letter and this was also cascaded to some surgeries for review.

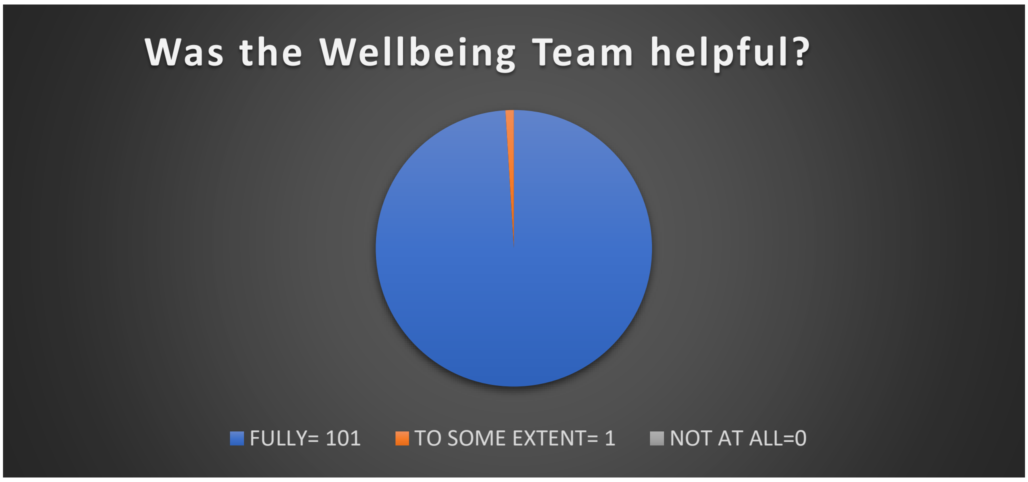
Prior to the start of the 'Think' pilot the invite letter was also put forward for reconsideration by our participating surgeries Patient Participation Groups.

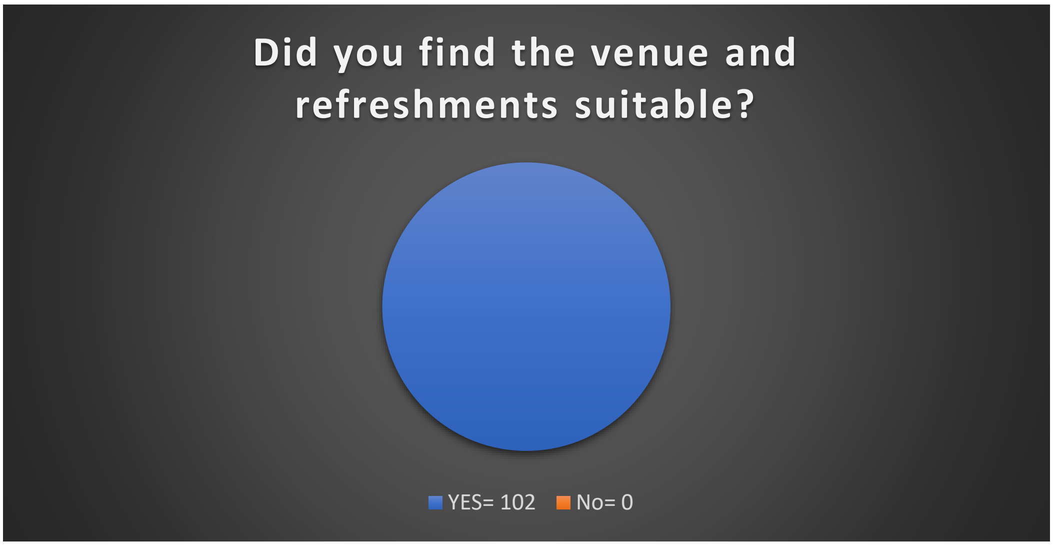
Evaluation Findings

Event Evaluations

We received **102** completed evaluation forms from the session attendees, who were given evaluation forms to give us their feedback of the event and its content.







Main themes: Most attendees found the sessions helpful and interesting and made them ‘Think’, with 100% stating they would recommend the sessions to others.

64 comments (Appendix 2) were also received on the forms, the majority of them positive, explaining that the session had given them the information they needed to think about their future care in an appropriate and sensitive way. Of the small number of negative comments received, these were about improving the contents of the invitation letter as it wasn’t clear what to expect from the session, its purpose, and why they were advised to attend. A few comments reflected that although the session was

useful some follow on support would be useful on ACP, or felt it could be difficult to see their GP to be able to act on the information received.

Findings from in depth interviews

Three interviews were completed from a total of 12 attendees who agreed to be approached for follow up. Two patients and one informal carer were interviewed.

Of the remaining nine: six didn't return the consent form after being sent the participant information sheet, two declined after receiving the participant information sheet, one was not contactable by phone.

Staff involved in both pilot GP surgeries were also invited for interview to gain their views and experiences of 'Think', a staff member from one surgery agreed to be interviewed, the other surgery agreed for their feedback they had already given to be used in the evaluation (this is included in the 'Summary of Revision - the letter' section below).

At the time of attending the session two interviewees already had both LPAs in place for health/welfare and financial affairs , one had just an LPA for finance and a Will.

One participant was a member of staff from a GP surgery involved in supporting the implementation of 'Think' in their practice.

With only four interviews to analyse the themes from the attendee and GP staff interview have been combined together in the findings below, although they were from different perspectives they sometimes did overlap.

Reactions to receiving the letter

Their first reaction was questioning why the e hospice was involved, or wondered why they had been invited or thought it may put some people off attending:

> My first reaction was, erm, 'Why is my stepdad being invited to a Hospice?' Because, like a lot of people, the first thought of a Hospice is where you go to die of cancer. And I wasn't aware my stepdad had cancer so, erm, I telephoned and spoke to a very nice colleague…but she explained that it was a selection that err… The GP had given names of people that potentially could be… find the service useful (G001)
>
> Because I think it mainly made people think, 'Oh Pilgrims, you know, it's end of life,' and as you say, the take up's slow probably because of that rather than the awareness that we are actually offering a package of services that are going to benefit you. So I think we've got to look at advertising on that front(S001)

Despite this expected reaction to some degree the GP staff member felt a letter was the best approach for inviting patients to 'Think':

> Well, bearing in mind that these are frail patients who are mostly and probably elderly, the letter is probably the better way because a lot of them aren't tech savvy or have access to the internet etc etc. So we have to be mindful for that, you know, the age range that we're writing to so I think, in this case, it was the right thing. (S001).

The booking experience

The booking process was considered to be 'very easy' and 'simple'. They liked the fact that there was a choice of dates and times. The person taking the bookings was very helpful and polite.

First impression of venue/session

They liked the location of the session in the hospice therapy centre, it was seen as a pleasant and friendly atmosphere, where as a GP surgery was seen by one participant as 'a bit clinical'. Attendees felt they had a nice welcome from the 'Think' team:

> Everyone was very welcoming, they directed us… you know, there was a nice Welcome Desk there and they knew exactly who we were and directed us straight along a corridor into the room and made tea and coffee. And yeah, it was a very nice atmosphere (G001)

They also helped one attendee who found it difficult to come in as a close family member had died at the hospice, and they were very appreciative of the support from the facilitators to help them overcome their fears of entering the building:

> …she came and sat beside me, held my hand and then we had a bit of a natter and she said, 'Shall we go and find a cup of tea?' She said, 'Do you feel as though you're ready to go in?' She said, 'I will come with you, I will stay with you.' And she was fantastic… There was three of them there, they were very, very helpful and very nice, very… what word can I use? Comforting. (P003)

Others commented on the size of the group, the group sizes were similar (15 and 17) but there was mixed opinion. One felt that it wasn't overcrowded and small enough for people to still ask questions. Whereas another was surprised at how many people were there, given COVID. The GP staff member felt that social distancing should still be taken into consideration for 'Think' sessions in the future:

> I'd like to carry on with [social distancing] because, you know, with this trial, they are a bit more vulnerable. So, you know, even though they say, 'Oh you can carry on as normal now,' you know, the vaccines will wane and, err, we still need to protect our patients. So I think the social distancing thing should still continue – maybe not two metres – but, yeah (S001)

Despite the positive reactions to having the sessions help at the hospice, some advantages were suggested in holding the sessions in the GP practice by the staff member:

> I think the sessions could be held in a practice, I mean that may assist a little bit: you know, if patients are struggling with transport or whatever, they can always get to the practice so that may be something to think about…I know in my practice you could probably fit probably fifteen maybe in, that would be at a push. You've got a large meeting room sort of near [GP surgery name]: you could probably get, I'd say, ten. But in some of the other practices, like [GP surgery name] for example, they have a huge meeting room and you could probably get up to twenty, maybe a bit more, in there comfortably. So yeah, they do have like meeting rooms but they all vary in size…so you may have to break it up so you have three sessions of ten or something or, you know, to make it a bit more manageable (s001).

Thoughts on planning ahead and why they had come

Attendees had decided to come not just for their own interests in planning ahead their own care but for the interests and care of others e.g. their family, friends and groups that would have a shared interest.

> … it's only thoughtful to plan ahead for your own care, death, because that's a loving thing to do; it's selfish to leave a loved one floundering, not knowing what to do in that situation (G001)

Others has done some or a lot of planning and thought it was worth coming to check they hadn't missed anything:

> For me, it was like a checklist really…I would say that there's a great danger in thinking, 'Well, I've done everything.' Life teaches you that you probably never have (P002).

What had they had learnt/taken from the 'Think' session

The attendees appreciated the importance of being able to attend a session like 'Think' and thought it was a needed service to support people to open up about future care at the end of life. One drew on the importance of the session through their own experiences when their father died who had nothing in place which made things really difficult to sort out their affairs.

> It's 'well done' to all those involved because it is important, as I say, and then the answer is: all those involved that produced something that the audience for needs to be ever increased.(p002)
>
> Well, I think it's a good idea. I know people think, 'Oh, I don't wanna go to a Hospice, I don't wanna talk about it,' but once it's out in the open and you're talking about death and money problems and things like that, it makes it a lot easier. So I think it's a very good idea (p003).

Despite having some people who were forward thinkers in terms of already putting plans in place they felt the session provided them with knowledge on areas of health and care that they hadn't thought about or were not so aware of:

> But it did actually broaden my thoughts because I thought about dying and a funeral cost but I hadn't thought so broadly about care (G001).
>
> 'cos you can think you're pretty up on things then all of sudden someone will say something and you think, 'Ooh, I haven't thought of that.' So it is, in that respect, it's helpful….I think I need to go through that paperwork first and get my ideas into some sort of order and so I will talk to [daughter] about the medical side of end… when I'm end of life sort of thing. 'Cos the money bit's sorted out, it's just the medical bits of it so… But I will get sorted with her.(p003)
>
> ..'cos when I chatted to some afterwards - other people in the group who sort of knew about it [LPA] because somebody had mentioned it, but had never got round to it and I think it added more than…without in any way causing people to panic… What I mean by that, I think it caused them to think, 'Actually, we need to go through these steps and not just Lasting Power of Attorney, but go through steps and just make sure that we're doing what we want to do.(P002)

Expectations

Similarly to the comments from the evaluation form, two of the three attendees were not sure what to expect from the session, but they felt that the session exceeded their expectations:

> I didn't know what to expect…If I knew what I was thinking about, it was broader than I thought it would be. So, yes, it did exceed my expectations (G001).
>
> I didn't know what to expect, to be honest, but having got there, …I'd got inside it was: I feel good. I feel, 'Ooh! I'm here, I've managed it and it's interesting – I'm learning different bits and pieces,' so it was well worth going (P003).

Actions for the future

All the attendees came away from the session with clearer plans to at least discuss plans for their future care and wishes with family members and friends, both for their own care but also for the care of others:

> I'm going to make sure I've got Power of Attorney sorted out; I'm going make sure everything's written down in a file so it's easily accessed; I'm going to have a Care Plan – she's going to know that I want tea in the morning and I don't need to get up before 8 o'clock 'cos I don't have to. She's going to know all these things, so I'm thinking forward again to myself being old and making sure that everything is in place so that caring for me is going to be as easy as possible for her. Because this is all going to be a burden, erm, but I don't want it to be more of a burden than it absolutely has to be (G001).
>
> … I will extend what I've done. I also… I will use - and I haven't done it yet, … I will use your two, the actual documents produced by Pilgrims, as part of this Wellbeing thing with my wife. The other ones, frankly, I'm better off distilling in the other documentation I've produced, which is much more simple. But I think these two documents you've got, she needs to look at.(p002)
>
> But I want to be more prepared and have a broader understanding for my parents' care going forward. And then I'd like to then be able to use the knowledge and experience that I've gained in caring for my parents to then help other people care for their parents or, erm… Yeah, just be able to make use of this experience and knowledge base to point people in the right direction to where they can get help (G001).

One had already started conversations with their family and hoped to use the materials and information given at the session in future which they felt would make the process much easier to have everything written down to help the family to make decisions in the future if their wishes are clearly known:

> So we had a little conversation – we did it on Zoom as a family in the height of the pandemic... But doing this broadens that process, and putting it down in writing, I think, is a much better idea. Because when you're in a state of panic and upset and you've got siblings squabbling about what's best to do, to be able to refer back to the 'Life Book', the Advance Decision or whatever, I think it's a great idea because you've got an anchor point that you could say, 'Well, regardless of what everyone's saying, this is what Mum wanted, this is what Dad wanted so that's what we're going to do.' (G001).

Presentation:

The presentation delivered as part of the 'Think' session was felt to be clear with relevant information, described by one as 'fantastic'. Another felt the accompanying documents helped back up what was said in the presentation and one liked the fact that they could ask questions during the presentation.

> But everything that was said, I think, was telling in the fact that you realised that actually these were good points, relevant points, and you need to go away and think about them…it's [the presentation] getting you thinking that you need to do *more* thinking (p002).

One-to-one time with the facilitators

All the attendees appreciated the additional time at the end of the session to have the opportunity to ask questions and speak to the facilitators one-to-one about anything they might have a query or concern about:

> People do need to speak one-to-one because there may be questions in people's minds and not everyone's comfortable putting their hand up and asking a question in front of everybody. (G001).
>
> I mean the coming to you individually was pleasant, polite and, you know, just giving an individual a chance to say something without others hearing it. But the question time, in my session, was very good as well… I mean, it reinforces that feeling that the organisation cares (P002)

> …they made you feel very welcome and you knew, if you wanted to, you could ask them almost anything: they put you at ease. (P003)

The session materials

The attendees were complimentary of the materials provided in the pack, described as 'excellent' and had 'nothing but praise' for them. One attendee had not yet looked at them but planned to in the future and was pleased to have them.

Some of these materials had been produced by Pilgrims Hospices themselves: the 'Talk Plan Live' booklet, and others were existing resources from Compassion for the dying person' and 'Age UK':

> The one that says 'Talk, Plan, Live', 'Time to Think' - they're extraordinarily useful 'cos they're giving you the bullet points as opposed to the detail that is in some of the other documentation and I think that helps as well because it gives you a topic and then you can explore your topic. .(p002)

There was praise for the Age UK 'Life book' which acts as a place to write down all the information for others to know all in one place:

> …had I not been to the 'Think' session, I wouldn't have known about the 'Life Book', wouldn't have known about the 'Compassion in Dying' website in order to get these print offs in order to have that conversation and be able to write it down. (G001 carer).

The 'Planning Ahead' book was seen as particularly useful to help explain clearly the topic covered and areas they may not have thought of. The life stories were also mentioned as helpful within the booklet:

> I loved the life stories, erm, and very clearly laid out… Because it's small and lots of pictures, it doesn't feel daunting – that it's too much information to take in – so that's very good.(G001).
>
> There's 'Planning Ahead' I liked best and that doesn't mean best because other parts weren't good. It was all good, but the 'Planning Ahead' thing takes you through a lot of processes that I think that some people can omit, or they haven't thought of and they're confused, and this explains it clearly. (p002)

The materials in particular, had been utilised since the session by the attendees or they intended to use them in planning their future care. One attendee thought the Lifebook was a 'fantastic idea' and had since ordered an additional five to give to family and friends.

The same attendee became aware of the *Compassion in Dying* website in the materials (in the *Planning Ahead* book) and has since had started to write an advance statement after the session using that website:

> I found a template, yeah, on the 'Compassion in Dying' website…We went through these with my parents… the 'Advance Decision to Refuse Treatment' pamphlet and the 'Advance Statement: My Health and the Future'. … Also found a 'Do Not Resuscitate' form and then printed that off and went through the 'Life Book' with them, so all four things I went through with each parent. Erm, as I said, I've still got to dot the i's and cross the t's but, erm, I've got them all completed so that I will put them away for the future. (G001)

The four areas: body, people, mind and place

The section of the session materials on body, people, mind and place, was the part that attendees found more difficult to take in and articulate. They found it difficult to think of these as separate areas and saw a lot of overlap. They did see all the areas as important to cover.

> Erm, well, as that little illustration shows on the front, they very much cross over, don't they? So, erm, we are one person and our needs cross over: our mind and our body crosses over. So you need all elements… It was… so it was interesting going through all of those points but they did all seem to merge a little bit in my mind (G001)

One attendee felt that more could have been included in this section on the financial LPA as they argued that although it is not health related having plans in place can affect people's health and wellbeing:

> In one of your documents, you very clearly state that there are two LPAs. But in one of your... I can't remember what it was… one of the others then only concentrated on the health LPA when, actually, looking at your money and investments frankly worries a lot of people so there's a health issue to them anyway…Whereas the truth is in people's – you know, whatever assets they own and where they're going to and etc etc – they're often stressful things happening in late life. So there is the health issue: they're not 'non-health'…. And I would bring those in under the 'Mind' bit.(p002)

Potential barriers to putting actions into place

Despite plans of actions there were some perceived barriers. Although awareness was raised about future planning and the different documentation to use and complete, none of them mentioned that they would involve their GP in their decisions, discussions or share their completed ACP documentation.

One attendee was reluctant to involving GP after attending the session, and decided to obtain a DNAR form from an alternative route rather than directly from their GP, even with the understanding that this wouldn't be a legally binding route. The question was asked in the interview about sharing their completed documents with their GP and they said that they had not thought about it but would be a good idea and something they would also look to do.

> 'It's DNAR form you get from the GP. So I haven't gone down that route 'cos of getting it from the GP. What I did was printed off not a DNAR but a DNR, which is slightly different. That is… I just found that at the end of… I think it was on the 'Compassion in Dying' website… So, yeah, as I say, I still haven't gone down the proper 'Do Not Resuscitate' with the doctor: I decided to go with the lesser binding route (G001).

The GP staff member was not aware of whether any patients had mentioned they've attend 'Think' and wanted to discuss further with their GP about ACP. However it is perhaps too early to see any impact in this way, and difficult to tell with a small interview sample whether other attendees may have similar reluctance or lack of awareness regarding involving their GP in ACP. A small number of comments from the evaluation forms did indicate that attendees felt it was difficult to access their GP which could have the potential for future lack of engagement with them on their future plans.

Although some found the 'Think' session helpful to open up further conversations about future wishes around death and dying with family and friends, one still found it difficult to broach the subject with their family. They had sorted the financial side but they didn't want to push the conversation any further yet with her daughter/granddaughter due to fear they wouldn't engage:

> 'cos her [daughter] attitude was, 'Oh [name], you don't want to talk about that.' I said, 'I do need to now while I still can.' I said, 'I need you to know what I want, what needs doing, what's paid for, what isn't and what's sorted out.' And she said, 'Oh but you've got ages yet.' I said, 'No, we talk about it now.' So I got my daughter over and my two granddaughters and they said, 'Ooh, do we wanna hear this conversation?' I said, 'Whether you want to or not, you're going to.' So we sorted it out so they all knew roughly what I wanted and what was going on if it gets… obviously not yet, I'm going to stay around a bit longer (P003)

Reassurance

All three of the 'Think' attendees found the session gave them a feeling of reassurance. Either in terms of verifying what they had put in place, knowing they were 'a few steps ahead' already, or knowing what else they had to consider and having the resources and support to move forward with it:

> I think, in my case, it's been reassuring. I can imagine some people will need to work quite hard to feel reassurance 'cos they've not covered a lot of it but that's the point of it: you want them to build their own reassurance because they've taken the guidance and taken the line of thought (P002).

> Because obviously they tell you about making a will, Power of Attorney and things like that and it was sort of… I'd done a few of the things and I thought, 'Ooh, that's handy, I've done that right,' you know and, 'Ooh yeah, I've done that,' and things like that so I was quite pleased. Because you do these things and you never know whether you're doing them right or not….But at least I know if I do need help, there's help available…. I can say, 'I've got my little brown carrier bag and it's got the bits in it.' And I keep looking and think, 'I will sit and do that, I will sit and read it,' (P003)

Suggestions for improvement

The sessions were well received by the interview participants, but some did come up with suggestions for how the process could be even better.

Improving the invitation letter and related advertising:

Although there was recognition by the GP staff member that the revised letter improved the process, the take up of the sessions was much lower than they had hoped. There were still ways in which some interviewees felt it could be further revised and also consider advertising alongside to increase take up by raising awareness of the programme so they were not receiving the letter cold, not knowing what to expect. It was also suggested that the letter template itself could have some changes to make it addressed from the GP surgery rather than the hospice:

> So if we completely changed that and put the surgery letterhead on there and perhaps put 'working in partnership with', and then put your little logo at the bottom or somewhere discreet (S001).

> Just from my recollection, so I think all you can do is try revising it [invitation letter] and sending that out again. I don't know how else we can do some advertising really…Because I think it mainly made people think, 'Oh Pilgrims, you know, it's end of life,'… the take up's slow probably because of that rather than the awareness that we are actually offering a package of services that are going to benefit you. So I think we've got to look at advertising on that front.(S001)

In terms of advertising and communication recommendations one interviewee felt the branding was right which they considered to be 'very attractive and modern'. A couple of interviewees had different views on how best to reach the target audience, the hard to reach groups in particular. Both raising awareness and making it attractive to different audiences was considered (e.g. using the surgery website, Patient Participation Groups, marketing people, and third parties who will see these patients):

> …on its [GP surgery] website and things, and there's been lots of improvements to try and reach people….But it may be that this programme that you've got, and I hope it is something which is having success and will interest more surgeries, it would be nice to have a simple summary of it on the surgery websites (P002).

> And the websites are where people naturally, and more frequently, tend to go to get information or to ask questions. And one the things that we'll be bringing on our website [GP surgery], at certain times, is to have what I call 'flash notices' and so you suddenly say, 'Well, let's this week, let's remind them about 'Time to Think' or direct them to find 'Time to Think' in the website.' So on that week it may say, 'Great programme to help you as you are getting older and planning your retirement: 'Time to Think'. Click here to go that page.'(P002)

> I think definitely the advertising; the communication - the way that we communicate with patients – erm maybe using some other agencies to support that information, Age Concern, you know, things like that; that the frail, know you, are in contact with…I mean we can put posters up and, you know, we put posters up in the surgery but clearly they weren't effective so we need to look at other ways of reaching out to them (S001).

There were additional comments made about the programme and the importance to them that it should try to reach the hard to reach groups:

> But the people who miss out most are the people who probably need the most help and they are probably the people who have the most stressed lives, lack money, etc etc. And it's how… I'm sorry, forgive me, if I was your Board, I would be saying, 'How do we reach out to the hardest to reach people?'(p002)

The GP staff member commented on how this was part of the discussions during the pilot set up:

> We had a number of Teams meetings…looking at the process, the principles and the outcomes that we would like to get from the pilot, and how we reach those hard-to-reach patients and the vulnerable patients. And, you know, change the ethos of Pilgrims: that it's not just for patients at end of life, it's also to signpost patients to a range of services that would assist them with their condition (S001)

They also commented on how they would like the programme to be broader in the future to be able to capture more vulnerable and hard to reach groups:

> I think we should look at a broader group 'cos, you know, I'm keen to capture as many vulnerable and hard-to-reach patients as we can, and the frail are in that bracket. So I think to go broader would be very beneficial.(S001)

Related to this, is to ensure the criteria for patients we wish to identify in the screening process for the GP surgeries is clear in a future roll out of the programme:

> Well the process was really smooth when you consider it was the first time we've worked in partnership on something like this and I think that was, you know, that was successful in itself. This went really well and I think we just needed initially to clarify the searches because of the amount of searches to start with, as I said, it was a few thousand. So I think it's just being clear on the definition of patients that we're looking to contact. Erm, but the remainder of it all went really well (S001)

Other suggestions for improvement related to changes to the session itself and the accompanying materials.

Use of the 'Talk Plan Live' booklet:

Two of three attendees interviewed suggested that it would have been helpful to know about the 'Talk Plan Live' booklet prior to the presentation, which they could have used to write notes during the session:

> So the 'Talk, Plan, Live' booklet… had I known that I'd had that in there, I would've definitely pulled it out and written the notes in the appropriate sections, but at the moment it's blank … there were little nuggets that came up out of each of those presentations but I thought, 'Ooh, I need to remember that (G001).

> Talk, Plan, Live', with the bullet points and then pages for jotting an odd note down, that might well have been useful from the beginning… the nice thing about it is it's got a good little hard back on it so that if you got a pen out, it wouldn't be like trying to write on one sheet of paper where your biro would go through into your trousers or your dress….It would be quite nice to say, 'Look you might want to…', when the session starts, 'Oh you've all got this 'Talk, Plan, Live': you might want to just jot a note or two in it as we go along.'(P002)

As mentioned above, one attendee felt it was important that the financial LPA was also covered sufficiently (they noted that the *Planning Ahead* booklet covered it but the others did not). They felt it was important to include 'non-health' aspects of planning as well as health, as sometimes these could not be completely separated, as these things affect not just the health of the patient but their loved ones as well:

> ….The point about it is, it's not just the wellbeing of the person who is saying, 'Have I covered everything in preparation for my later life and then eventually when I die?' It's the impact on the other people who that is going to affect.(P002).

Option to receive information in alternative format to refer to again:

Two of the attendees felt it would be helpful to have the opportunity to have received the information in a different format to be able to refer back to the information at a later date. They didn't specify an alternative format but would take the opportunity to listen to or see the presentation again to be sure they had captured all the information that perhaps they hadn't been able to during the presentation:

> I remember thinking when I walked out of there, 'If I could just sit through that again just to make sure that I've got it all,' because, erm, sometimes you can get… When you're listening to a presentation, err, it's like you hear someone go, 'Right, point 3….' and you go, 'Well, what's point 1 and 2?' You almost need that erm… which we had a lot of… each visual presentation as well, so that you could see where you were in the presentation and be able to look back and get the whole thing clear in your mind, walk out there and go, 'Okay, yeah – got it.' (G001)

Another attendee felt it would have been beneficial if links to the materials, which they felt had 'great content', were also given digitally so the information they want their family and friends to know can be more easily passed on for those that are more technically able:

> the missing element from my point of view… we're in a world that is increasingly technical and digital and whilst it may be true to say that the older brethren are less technical on average, they're all getting more and more and more technical and it struck me that these excellent documents, including those that are there for you to fill in, should also be available digitally. Because if you have them digitally, you can share them with family very easily instead of trying to copy something, (P002).

The process of running 'Think' for GP practices:

The interview and feedback from the GP surgeries involved in the pilot themselves highlighted themes around the process of running the 'Think' programme, in terms of generating and validating the patient list with the screening tool, the letter generation and mail out, and the response from patients.

For the pilot surgeries the screening tool had the potential to generate a large cohort of patients all of which would be too much to invite in one go. The GP practice staff member suggested the cohort and numbers of letter this could generate needs to be carefully considered in any future roll out to make sure the implementation of 'Think' is manageable for both the practice and the hospice. The practice found themselves having to be selective due to the sheer number that could be generated:

> So we're obviously using EMIS Web [patient record system] and we could set up searches in EMIS, which is what we did in this case. We've got a large number of frailties so we had to be very selective in the age range and conditions that they had, which then brought the numbers down: otherwise, I think, numbers were just too high to be included in the pilot(S001).

Despite this they still felt they should look at a broader group to capture the more vulnerable and hard to reach, and thought it should be considered in the future roll out, as mentioned above.

When asked about the validation of the list they felt this went well initially , but as mentioned above it was the quantity to deal with at one time with the number of people with frailty that was generated. However the generation of the letters themselves was relatively easy:

> It went well, I think actually. I think it was a bit labour intensive but it was right… I don't think the pulling of the list was such an issue to start with. I think where it was quite intensive was the letters: getting all the letters out to patients and the information, which is fine. It's not an issue but it was just admin quite heavy, getting the letters out. (S001)

> It's very easy, I mean we can do a mail merge pull the addresses off, pop those on the letters and then off it goes in the post. That was fine – it was just the number of letters.(S001)

As a result of this experience they suggested that a dedicated admin support would be needed for any future roll out. Further discussions would need to be had about any future roll out, in terms of the frequency and regularity of mail outs i.e. how often it happens and what it might look like, particularly if the numbers of identified patients are large.

Queries from patients were received after receiving the invitation letter and some amendments were made to the letter and a guidance script developed and given to surgery reception staff so they knew how to handle any calls they might receive (the process of these revisions is described in the 'Summary of revisions' below.

The GP staff member felt these changes saw improvement in the reduced number and type of queries received and staff were better equipped with the knowledge on how to handle them:

> It did improve after those changes and I am… I do know that. So yeah, that helped… And I think this is just something that is just going to be learning as we go. Erm but yeah, it definitely helped making those changes.(S001).

They were also complementary of the process of working together between the GP surgery and hospice to set up 'Think', and it helped to be linked with a dedicated person at the hospice (the 'Think' programme Manager) who they could get in contact with if they needed:

> When [Think programme manager name] came, with her… we had all the guidance and assistance we needed: we knew where to go for the Single Point of Contact if we had any queries and she always responded in a very timely manner and was always very helpful and always somebody that we could call on if we needed any support or had any queries or anything. So that was excellent – thank you(S001).

Thoughts on future evaluation

Finally, in order to help plan the future evaluation of the roll out of 'Think', interviewees were asked their thoughts.

Attendees found the process of taking part in an in depth interview relatively easy and not too demanding. They were however individuals who considered themselves to relatively well or had attended as a carer of someone else:

> It's a good idea and it's been very easy to talk to you… very easy (P003).

> I don't feel as though I've been on Zoom for an hour…and it's nice that you just placed questions and let me waffle…and then bring me back. That's nice that I can talk freely and you've given me plenty of time , we've not been rushed (G001).

In some instances the interview took longer than initially suggested it might take in the information sheet, so this should be amended to take around an hour if this method is used again in the future.

The GP staff member had some suggestions for the future roll out to look more at the demographic breakdown of the generated patient lists from the screening tool, to see who did/did not attend and understand more about why people chose not to attend:

> So we could've looked. We could've set up in EMIS and we could've look at those demographics: that wouldn't have been difficult to do. But I think, because we didn't identify it at the beginning, it wasn't included so probably for the next round, that would be something that would be good to include (S001)

> …definitely getting more feedback from the patients so, for instance, the people that didn't attend: I think we need to target them because I think the messages will come from those as to why they didn't see that it was beneficial or why they didn't want to attend. And we need to work on that, I think (SO01).

'Think' Staff Reflections

This part of the evaluation analysed the reflective templates of hospice staff involved in the delivery of the 'Think' programme. They were also used by staff to support with any changes/adaptions to the 'Think' sessions following learning and reflection.

Two completed templates were received from the 'Think' Programme Manager who was involved in the operational tasks involved with the programme: session bookings, fielding of general enquiries, liaison with the GP surgeries and general support during the 'Think' sessions. Nine completed templates were received with the reflections of the facilitators running the sessions. These were completed by one Facilitator on behalf of all the facilitators involved, after each set of sessions on a particular day (usually two sessions).

Operational staff reflections

The staff reflections of the operational tasks related to the response to the first mail out with the original letter and further reflections following the mail out with the revised letter.

Early on the phone calls received were a mixture of both positive and challenging, some patients were very happy to be invited and others responded with anger and upset. Nearly all of the callers asked what 'Think' entailed, what's it all about and why they have received this letter in the first place. This was similar to what was found in other parts of the evaluation from patients and GP staff that the letter was unclear as to what to expect from the session and why they had been selected. For some there was misunderstanding that they hadn't been told about a serious condition and needing hospice care.

Suggestions were made by the manager and the GP surgeries for revisions of the letter and a guidance for call handlers which are further described under 'Summary of revisions' below.

With their experience and background the programme manager felt capable in handling the more challenging calls but felt someone else taking on this role in the future would need some level of experience and communication skills training to handle angry callers or calls where the people were upset and anxious about the letter which would need a different style of response.

After the revision of the letter reflections of the programme manager were that overall there was more understanding of what the sessions were about, even naming the ‘Think session’ which did not happen before. The phone calls were more positive in general with a smaller amount being described as challenging – these calls were more just from people asking why they have received the invites in the first place and some still unsure of coming into the hospice environment and thinking it is about hospice care. The manager suggested therefore that the letter should be reviewed again before further roll out.

They also felt that the use of other venues, even surgeries in the service roll out, could alleviate the small concern that some callers had about coming into the hospice. Although the manager did observe that once people attended the Therapy Centre they are usually suitably impressed with the room and grounds of the hospice, which aligned with the responses from attendees in other parts of the evaluation.

They mentioned that we also need to be aware that the letter may land at a time that is not good for the recipient i.e. one caller stated that her husband got the letter the same day that he was diagnosed with terminal cancer so this felt very inappropriate to the family. Particularly in this instance it would have been a case that was unfortunate timing. It does then lead to consider whether recent or pending terminal diagnosis could be picked up during the screening and validation process to enable a judgement to potentially omit them. However, would this be practical with the number of patients involved, and is it what others in a similar situation would want?

‘Think’ Facilitator Reflections:

The vast majority of session reflections (7/9) were positive overall. With two having some challenging elements.

Early on some amendments to the content of the presentation/video were suggested (e.g. where there was repetition) and additional information on Marie Curie ACP resources to be provided, and all were actioned for future sessions.

Positive feedback was received during the sessions, with attendees overall being very engaged. At one particular session the facilitator reflected on how many people felt relieved to be given 'permission' to have these conversations. Regularly many asked for a ACP development session as something to offer as a follow up to attending ‘Think’. Feedback at one session was for whether ‘Think’ could be expanded to a broader group (e.g. over 50s). Some commented that they would have liked to invite additional family/friends if they were able to. They noted that every group appreciated the opportunity to be able to talk individually with the facilitators following the presentation, and one facilitators reflection noted the richness of this part of the session.

Some negative feedback was also received about the letter (similar to that described elsewhere in the report) which did dissipate over time as more attendees had the revised version of the letter. The point was made by attendees at a couple of the sessions about difficulties in being able to access their GP to register their ACP.

The size of the groups varied per session, and the facilitators found it harder to present if the group was too small. Sessions ran with between 6-22 attendees, with an average of 15, which was considered to be a good sized group.

Over time they found that providing the information bags up front as they entered and registered worked well and also having some spare bags were useful to give to interested guests of the patients.

There were many practical issues that arose, which will need to be considered for the future roll out, particularly if going to unknown venues outside of the hospice and at times such as evenings and weekends when they may not otherwise be open and doors may be locked and alarms on etc. Therefore the need to ensure the environment is fully ready, is important when holding sessions off site. Other practical issues to consider for the future were:

- one clear entrance for attendees (there were difficulties due to ongoing works in the hospice reception)
- Need to check for attendees with visual/hearing impairment at start of session to ensure they can see/hear ok
- ensure screen is large enough for people to see in selected venue.
- ensure there is enough space around furniture for walking aids and wheelchairs

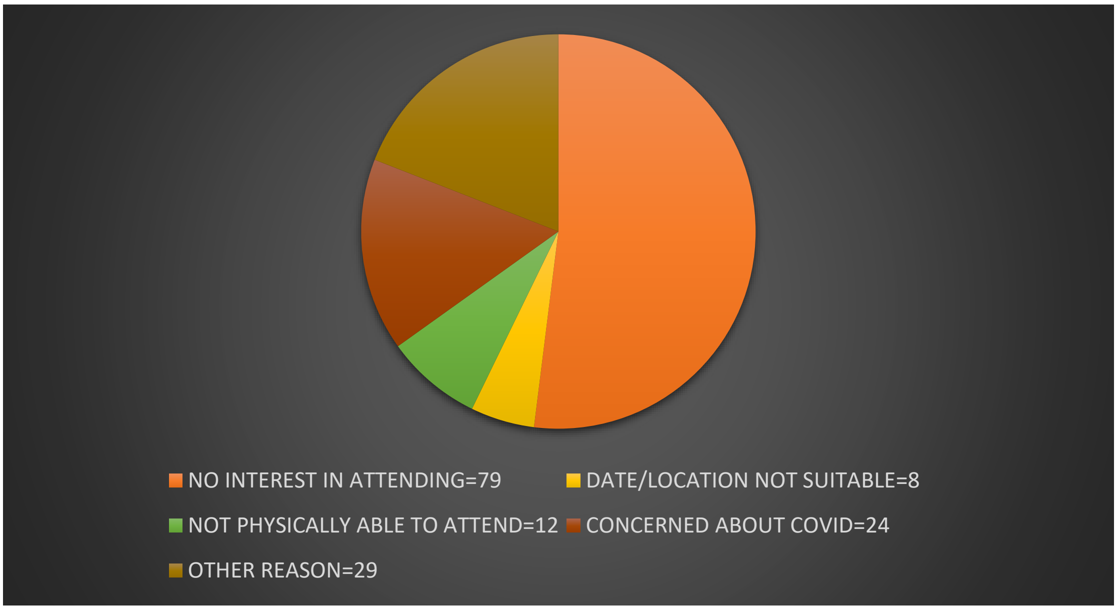
The final reflections of the facilitators after all sessions was that the presentation has changed since the first few sessions, in response to feed back, and now flows much better with less repetition. They reflected that there are questions / themes that come up each time and that every group has appreciated that time talking on an individual basis after the main presentation. To look ahead to the roll out the facilitators will put together a FAQ sheet for future presenters to use at a later date. Other final reflections were:

- The presentation and talk can be done in an hour.
- When held externally there probably isn’t a need for tea and coffee (which were provided) but it was a good way to relax people who were nervous about coming into the hospice but created extra work. Could possibly consider jugs of water/squash and attendees helping themselves.
- The maximum number of attendees would need to be around 25 for two facilitators to manage.
- In terms of who could facilitate these sessions in the future, they felt very early on that this would be difficult for volunteers only to manage. It could be run by a wellbeing practitioner role if trained with competencies.

Evaluation from Non Attendance Questionnaire

We sent **1050** questionnaires with each invite and **14.3 %** were returned (150).

Of these the following was noted:



Main theme : Over half of our returned questionnaires (52.7 %) advised us that they had no interest in attending our events. Further analysis of the comments received (Appendix 1), just over half (38/75) indicated that there was lack of understanding that this was preparing for their future. e.g. unsure why they were selected, not thinking they were at the stage of needing it yet. Some felt that they were able to support each other in their family, others who were carers replied to say that the patient invited was unable to attend due to their health, when it could have been useful to them as their carer. There were also comments on the part of the letter that said those invited had 'complex health needs' and there was lack of understand of what this meant and how it applied to them. This feedback (as well as feedback from the GP surgery involved) prompted revisions to the invitation letter during the pilot, described below.

Summary of Revisions

'The Letter'

The 'Think' invite letter was first created during hospice staff and volunteer focus groups and was also taken to a Clinical Commissioning Group in east Kent for review and comment.

The Invite letter was also taken to both surgeries Patient Participation Groups for review prior to starting the pilot.

After our first surgery mailing it became very apparent that the following line ,***'This service is designed for people like you living with complex medical needs'*** was causing concern.

Our callers were asking to explain what the sessions were about and whether Pilgrims had seen their medical records due to this comment. Some callers were upset and angry to think their records must have been shared with the hospice and the surgery were also getting many enquiries from patients who were concerned that they were not being honest about their health conditions, especially as they did not understand why the hospice was involved and assuming this meant they were at end of life.

At our first ‘Think’ session this was also brought up by some attendees.

We immediately took the decision to omit this line completely from the letter for the next batch of mailings and the letter was updated straight away.

Once we had started with our second pilot surgery, they advised that they were still getting many enquiries as the letter was not clear enough and their patients were very concerned over why they had received it in the first place, what it is about and why Pilgrims were involved and some also showed concern about coming into the hospice setting for the events. We devised a ‘crib sheet’ to support the receptionists who were the ones dealing with the concerns directly. This gave some key points about the pilot to be used when handling these concerns. This was well received but it was still felt by the surgery that more information was needed to be added to the letter and it was decided that no more letters could be sent until the letter had been updated to address their patients’ concerns.

We called an urgent project meeting to discuss the need to support the surgery as this was causing much more work for the staff involved. We revised the letter and sent this to the surgeries and PCN lead for review and it was agreed to continue with the mailing schedule, this change was implemented within one working day.

We checked in with the surgery after a few weeks to enquire whether the new letter had helped. The surgery advised that whilst they still had a few queries, it was not as many as the first time so they felt that it seemed to help quite a bit. We had also noticed on the booking line that the ‘theme’ of calls had changed and many were just asking to be booked onto a session rather than asking what ‘is this all about’.

Recommendations

- Further revisions for the patient letter should be considered to help them understand what to expect, why they have been chosen and why hospice involvement, that they may not need additional care now but the session will help to plan for their future. Adapt the letter and the header so it is clear it is from their GP and not the hospice. In addition to the report, also refer to the comments from the “opening doors to research group” who reviewed the letter in June 2022 after the pilot.
- Consider additional advertising to raise awareness of the programme through the GP surgery and other third parties who will see these patients to hopefully increase uptake if they receive a letter (e.g. via posters, flyers, website, tv screen in waiting area). Also consider what method may work best for hard to reach groups who may not be so likely to attend.
- To ensure the processes and procedures are clear for how to select patients from the list, when their cohort of moderately frail patients may be very large. This would be to avoid exceeding capacity to manage a letter mailout or book into ‘Think’ sessions. Some dedicated admin at the GP surgeries was suggested to deal with large volumes of letters.
- Consider presenting the ‘Think, Plan, Live’ booklet at the beginning of the ‘Think’ session so that attendees are aware of it and can use it during the session to write notes if they wish.

- Consider offering to supply the presentation electronically so that attendees can refer back to it and access the other materials electronically if this is helpful to them in their ACP e.g. to send to relatives etc.
- For future sessions a minimum of two facilitators is recommended. The sessions should continue to include one-to-one time for discussions between attendees and facilitators. The time of sessions should be during the day weekdays/weekends as evening sessions were not popular.
- For future evaluation: It was felt important to understand who wasn't taking up 'Think' as well as who was. This will be important to consider in the evaluation for the roll out to see who the programme is and isn't reaching and potentially benefiting. Take up of interviews following invites was low (25% for attendees) and only one staff member for GP surgeries, so some consideration is needed on future evaluation design to help uptake. Interview participants were otherwise happy with the process (the interviews took approximately an hour and needs to be amended in the information sheet).

Conclusion

Overall, the 'Think' programme and it's evaluation method are recommended for further roll out with some minor amendments. The programme was seen as successful, of benefit to attendees, and acceptable with same amendments by the GP surgery and hospice staff involved. A larger evaluation of the roll out of the programme to other areas and over a longer time to follow up patients would be recommended to understand if the 'Think' programme has a positive effect on patient outcomes relating to advance care planning and end of life care.

Disclaimer

The 'Think' programme was created by Pilgrims Hospice in east Kent, led by Wendy Hills. Copies of the 'Think' materials are available for use with permission from the hospice.

Please contact Karena Marks: karena.marks@pilgrimshospices.org for further information.

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Appendix 1: Comments received from Non-attendance questionnaire:

1 *Thank you for mums invite, she has asked me to just tell you that for now we are still enjoying normal everyday routines. Although mum has lots of ailments she still manages to do everything indoors that she wants. I live with my mum so look after everything she needs so had no worries in anyway. Mum has a big family luckily. Once again thank you it's nice to know we can come to your group if we need to*

2 *Dear Sir, Thank you for the invitation to the Pilgrims Hospice informal event, but I cannot understand why I was invited (By GP surgery name) in the first place as I do not live with COMPLEX medical needs, apart from my arthritis and a few niggles which can be sorted out and I have no current or future needs I can think of, Thank you*

3 *Thank you for thinking of me*

4 *Thanks for the offer but I am not aware of any complex medical needs so would rather the space went to someone one who needs this help*

5 *Not aware of complex needs*

6 *Mrs XXX is in [Hospital name], I am her neighbour*

7 *Thank you for the information*

8 *I am 89 years old this year. Have heart failure, live alone and do not want to catch Covid. Am reasonably fit for my age, I live alone but have a good friend who looks after me- am reasonable fit for my age*

9 *Don't think I am going to die yet*

10 *I am at dialysis every Tuesdays, Thursday and Saturdays*

11 *Because of Covid I am in my late seventies, and according to my letter my medical needs, I am going to decline the invitation to attend the meeting. I would however like you to send me any leaflet etc by post to the above address*

12 *Already have very good support system. I have 2 daughters, 2 brothers, 1 sister in law who all live close to me and already are 'there for me' should I need any help. I also have very good neighbours, 1 with a key to my house and contact details of my family. Thank you for the invitation*

13 *I am lucky to have a good mental capacity. My wonderful son and daughter look after my needs and are helping to make my home more suitable for my current and future needs. I have been living with xxxx Which affects my balance which I was told would happen because of taking xxx for over 30 years. I am very conscious of taking care not to fall over*

14 *I have high blood pressure just feel a little light headed at times*

15 *I don't think this is relevant to my mum. Thank you for the invite. Ps also times not suitable*

16 *Sorry for nagging you*

17 *Would like more information*

18 *Family provide care and help with daily tasks. Daughter lives with me so no need for outside assistance*

19 *I will be on holiday*

20 *I am XXXX, I am not physically able to attend these sessions, is it possible to have information sent to me by letter, telephone, text or email. I have not got a computer. I hope you can help me, I am very interest to get information about these session*

21 *I would like to know why I was picked for this invitation*

22 *Sorry I can't attend these dates as I am waiting to have dental work done as soon as a dentist can come to [town name]from a [Hospital name].*

23 *Whilst I am a supporter of Pilgrims Hospice I can't see how these talks are relevant to me. However, thanks for the invite!!*

24 *Thank you for the interest shown in me. I will be interested in any further information which is written as I am hard of hearing*

25 *My husband has Parkinson's and can't be left. I can't walk far, have a very painful right knee*

26 *Can you advise me why it is thought I should attend? Thank you for your help*

27 *I was given your number, but I felt I was being palmed off as I was told my high BP was due to stress. 176/95 I am waiting to have an operation when BP goes down. I am now on tablets to lower BP which is working. I don't want to take a place from someone who could do with help. Who genuinely has stress and depression*

28 *My mother has dementia and would not be able to take part in this session*

29 *Thank you for considering me for these sessions. It may be something I would do in the future*

30 *Husband in hospital very ill, avoiding mixing with other people so I can visit him*

31 *Seriously ill in hospital*

32 *I appreciate the thought. My husband does not wish to attend, Many thanks*

33 *I have osteoarthritis in both knees, I am obese, I have AF. Does this constitute Complex medical needs. I need help to reduce my weight but cannot get any*

34 *I have no interest in these sessions*

35 *Thank you for your interest in my health, But I am able to take care of myself*

36 *I am not aware I have complex medical needs. My partner has complex needs having type 1 diabetes, has had respiratory problems in the past but is now well and works 4 morning a week as a welder. He lives independently, but does have support from myself dealing with his diabetes.*

Not really sure how I have received this invite, would be pleased to attend if our circumstances changed, but at present we are both very well

37 *Dear Sir/Madam, Thank you for the invitation. At this moment in time we have all the help we require from family etc. But will contact you if help needed in the future*

38 *Thank you for inviting me but I will not be attending. The guilt and anger has gone and with everyone's help we done our best for XXXX. I am building a different life now and feel confident about the future, Thank you*

39 *Thank you for the invitation. Due to several health issues I feel unable to attend*

40 *I do not feel the need for this service at the present but thank you for inviting me*

41 *Well looked after, Thank you*

42 *I am not really sure why I have received this in the first place. is this relevant to me ?!!!!*

43 *I have completed this form on behalf of my husband xxxx- He is unable to attend at this time, Many thanks*

44 *I attended a similar session when my husband was dying and I have no need of another. I am sure it is useful and kind and is of use to some but not for me*

45 *I would not be able to attend there as I have bad Lymphoedema and don't drive and not able to get a lift there, I really can't walk far at the moment as my legs feel like lead. Thank you for the invitation*

46 *I do not wish to participate at present but thank you for the offer. I do have reservations about these being sent randomly. If a patient is having mental issues or stressed at the current Covid situation/conflict in Ukraine and its effects on so many people and countries, I fear they may interpret receipt of such letter meaning they have physical problems needing end of life care and 'tip them over the edge'*

47 *The only days I could attend would be Wednesday/Thursday. Would I be able to bring the patient? Or could I attend by myself and relay the info? Thank you*

48 *it seems a little premature*

49 *I am attending as a guest with XXXXX this Saturday March 26th 12.30*

50 *I'm not that ruddy old ! I've recently re-married and feeling well and active. I'm annoyed to think that my G.P considered I needed this service. I do not intent to become an 'old codger' just yet-sorry*

51 *My husband has Parkinson's and cannot be left on his own and my right leg the muscles are weak and I have a job to walk. We don't have a car. I had Polio when I was 3 years old*

52 *Since my 30's I have cared for my father and mother till their deaths. We have also had living with us, at different times, two aunts and an uncle, and then my sister until her dementia made it too demanding for us to cope with. I then being 70 we also have a small holding with animals to look after and a productive garden and orchard. My 93 year old husband and I support each other, ably assisted by our two married daughters and their offspring. When transport or any other help is needed. From our experience, we do not need teaching , as a family, how to care for the elderly*

53 *Thank you for your invitation. However I will not be attending. I am a cancer patient and have had many treatments. I have been very depressed over the last year and a half, but have been positive of late. Receiving this letter has made me rather upset and I don't really want to think about Hospice care. My husband and I are hopeful of many more years together*

54 *I have LPA's in place, so my 'children' will be able to make decisions of this type for me and I know they will have my best interests at heart*

55 *Now have carers living with me*

56 *Sorry, am unable to provide any information that may be of use to you, however thanks for the offer*

57 *We have already discussed and organised care and legal documents for our future*

58 *I have made a living will*

59 *Id not been told my cancer was life limiting. This letter came out of the blue and I found it very upsetting as I didn't know my condition wouldn't improve. I've not been told anything even that I had a new lesion, I only found out my letter from Dr Waters even though I had seen him only 2 week before*

60 *I already have a Health and Welfare Power of Attorney in place- Thank you for the offer*

61 *I don't feel I need this. I have sorted my own LPA out and have my own will- it's all under control. I was shocked and upset to receive this letter and by how it was written and that it is to be held at the hospice. It made me feel that I was about to die. The letter is awful, too wordy and too clinical. I have spoken to your lady on the phone and feel better now and she has made it easy to understand, it needs to be explained more simply and gently in the letter, so as not to raise concern. Also my friend said 'Pilgrims' are probably after money but now realise this is not the case. Thank you for the invite anyway*

62 *I shall be having cataract removal, will be in touch after a few weeks, Thank you*

63 *I have already attended the session with my partner for it very good. So will not need to attend again, many thanks*

64 *Significant small vessel disease (xx/x/xx) MRI SCAN*

65 *Thank you for the invite*

66 *Thank you for the invite but not for me*

67 *Due to major surgery*

68 *I would be interested if you do another set of sessions as I have been very busy these last few months, and therefore not able to fit in with your dates, apologies for the late reply*

69 *It would be nice to think a doctor would be able or willing to see me before things gets to a position that I would need your hospices requirements*

70 *My family know my wishes for the future and I have support*

71 *Very uncomfortable being with other people, after several panic attacks I realised I couldn't do it- very sorry*

72 *As face coverings are only 'optional'*

73 *A 'wobble' with Mr XXXX's health. We were very pleased to be sent this correspondence. We have DNR's in place at the GP's and the forms at home. We are aware of hospices but not sure of what they provide or how to contact them if we feel they could help. We have discussed 'end of life' with each other and our daughter but anymore information would be really helpful. Hospices are not spoken of in general and they should be. It's part of life*

74 *I am unsure of just how appropriate this is*

75 *Sometime in the future I may be interested just felt it was wrong time for me. I'm only 65 and not sure I'm ready to look round*

Appendix 2: Comments from Think Session Evaluation form *:*

1 *the importance of the legal side of matters sorted i.e. 'will'*

2 *very interesting and brought up matters we often put off, should be made available to more people.*

3 *improve content of invitation letter*

4 *presentation was very good and informative*

5 *a good way of starting conversations*

6 *in the presentation you mentioned about telling your doctor. help! you are so far down the queue when you phone you put the phone down. there needs to be a way to speak to a doctor so we could pass on our wishes.*

7 *impossible to speak or see a doctor. so far long on the phone.*

8 *would be nice to invite a relative or carer to attend with a contact to them by phone or letter.*

9 *well-presented think the printed material will be very helpful*

10 *follow through would be helpful. kick start a conversation later if not taken up at the time. provides an excellent opportunity to start a conversation and helpful it to come from outside.*

11 *gives you loads to think about not just the person I care about also myself*

12 *at this moment in time no but I am sure things will come in time*

13 *it has made my wife and I think about the future- although we are both in our 80's and active. we think your presentation will make us look into all the points made. some elderly people need help with the internet- maybe courses could be arranged for the over 70's.*

14 *really gave things to think about. very helpful.*

15 *didn't really know what to expect. think! a very appropriate word. it has certainly made me do just that and more! thank you.*

16 *online' is a feature, an increasing feature of modern healthcare. many older people cannot use 'online' effectively at all! disadvantaged- thought 'online help groups'. often, those who are least able to look after their needs are the ones who miss out on help. focus on xxxx to the least able.*

17 *useful to know you can discuss this with the gp practice and that they are supporting this. also did not know DNR was not legally binding.*

18 *I will have a think and feedback to charlotte*

19 *I appreciated the small, intimate group. too many people make me nervous*

20 *really useful made me realize things that we needed to do. would have been useful to have someone from age concern also in attendance.*

21 *having had time to think a second session to develop thoughts*

22 *a lot of thought has gone into the session giving food for thought and where to get more information. many thanks to the team.*

23 *more about the importance of LPOA. how to get your family to absorb the information, as many family member don’t like to talk about things.*

24 *quite frightening as have not thought about any of these situations. will discuss with my family at some point.*

25 *the letter that comes from the surgery could have a bit more information on it. as it stands when the letter arrives it leaves you feeling a bit panicky as to why you have received this letter.*

26 *very interesting.*

27 *no1- the original invite letter didn’t tell me what to expect.no5- if the invite was more explicit. the fact that one doesn’t ever get to see a gp makes a lot of these things difficult. however an interesting afternoon.*

28 *the session was very useful in opening our eyes to difficult subjects in a clear way. we will certainly follow up and put in place all that we can, thank you.*

29 *I was invited to partner my friend. we both thought the session was going to be about hospice care. not what we expected but very interesting.*

30 *a step by step guide to itemise main prompts and responses i.e. poa: welfare- y/n financial- who. dnar; in place- y/n. cremation; y/n, cemetery: y/n. will: in place- y/no- where. care home/home: preference. family/friends as carers: who. medicine: any prescribed y/n name. undertakers: who. personal wants .e.g. likes/dislikes. have: dentures/pacemakers/glasses/walking stick/hearing aids- y/n where.*

31 *to possibly talk about the subject of funeral planning. an excellent presentation.*

32 *very informative*

33 *if they carry on with this system they use, you couldn’t ask for better, plus I felt at ease throughout the session.*

34 *it covered everything I expected.*

35 *I think it would have been helpful if I had been advised why I was invited to attend prior to this event. that said I found the session most helpful especially the chat afterwards.*

36 *I must admit to thinking it would be about dying !! I had no idea of the existence of advanced care planning. I found the session to be very informative and helpful in assisting me in the future.*

37 *very helpful as it is.*

38 *I have already prepared for some of the things covered, but it is useful to have received the items not covered.*

39 *information what you want for end of life, who to inform etc*

40 *very informative, will encourage a frank discussion within the family*

41 *advice on funding for future care if needed*

42 *advice on funding for future care if needed*

43 *really pleased we came. definitely got me thinking even at 61 years. the session and ladies very clear, helpful and welcoming. thank you :) if there are any other different sessions I would be interested.*

44 *a- what a relief to have some helpful information towards the 'lovely' end of life! b- group (if willing)= introduce themselves to, perhaps, form a social group to support each other. c- perhaps*

some more meetings by professionals such as will writers, funeral directors etc (harsh but essential ?)

45 *comprehensive coverage of a difficult topic*

46 *110% to recommending to others. not just for people of our age but for others.*

47 *was really helpful and makes you think about different things. all very helpful- thank you.*

48 *could have more info before coming on letter*

49 *ask the attendees if they know someone else who could benefit from this information*

50 *to know who you get help from if you wanted to stay in your home. home helps companies etc. well done for putting this together.*

51 *it would be helpful to know where to go for help to get care in the future*

52 *possible to have advice from benefits advisor may help in some situations*

53 *although the information was in the pack. I thought the font could be bigger on the screen for those with poor sight.*

54 *I found the session to be a useful guide to planning- it was a birds eye strategic view. The associated paperwork looks promising with regard to finding out further info of particular interest. I'd be interested in sessions working at a detail level perhaps segmented by topic (e.g. place) or by groups (e.g. for diabetes).*

55 *session really whetted my appetite for more info- are you considering doing further session on place, people, mind, body for more in-depth discussion or when we have started our care plan? the team were very well trained and very informed, answering questions with ease, excellent !*

56 *this was very helpful, it made us think about things.*

57 *would like to put questions as the topics raised. thank you all, time to talk at the end was good.*

58 *we thought this session was to see a GP to discuss medical issues following Covid lockdown and to find out how my wife felt in general. it was a surprise to find out the meeting related to preparing for future old age care issues. the meeting was very informative just not what we were expecting.*

59 *I am not very good with words, but Karina, Annie & Justine, I think I have got all the names right !! were more than kind and helpful. made everything very clear and simple to understand. thank you very much.*

60 *this very good and would be great for all people from 50 years and up to be able to attend and learn of the facilities and helps available.*

61 *having an example of the LPA (finance and property health) filled in so we could see the sorts of items it was important to include. 'official' forms can be daunting to many people, so it would be useful to see one.*

62 *for me, as well as others, I feel sure, is facing these ongoing difficulties and weaknesses which seem be becoming more real as our years advance (I’m 85 now) and I think these meetings are good on the whole to make us all more aware of being these ages that we are, and a bit what we are going to do about it. P.s having worked in NHS on and off 50 odd years and many family too, I have gone quite far on this.*

63 *more advice for those who are not thinking yet about end of life.*

64 *I think this is a really good idea. I attended with a friend who has used the facilities at the hospice before so I didn't receive all the info in a pack but what was said was informative and sensitively presented.*