My Future Care: future planning in the community, by the community"

Thank you. My name is Zoe Harris, I'm the founder and CEO of My Care Matters, a not-for-profit social enterprise with a mission to improve people's experience of care in any setting, whether hospital, care home or in their own home.

Four years ago we launched the My Future Care project and I'm delighted that a representative of one of our partners, Henfield Community Partnership is also here today, so **I'll** give you some background and say a bit about the project, and Dawn will explain how they're making it work on the ground, in their community.

So let me start by explaining what led us to develop the My Future Care project.

It started back in 2010 when, to help carers support my late husband who was living with advanced dementia, I developed a really simple wall chart to share some at-a-glance information about him.

These were things he'd have talked about if he'd been able, but he wasn't able to communicate in the conventional manner, so carers looking after him knew nothing about him.

That wall chart, which we called the Remember-I'm Me-Care Chart and variations of which went on to be adopted by over 1,400 care homes, showed me the power of sharing information in a meaningful way. In other words, collecting information for a care plan to demonstrate to the inspectors that you know about the people in your care, is not the same as the people on the front line having immediate access to the information that can help them do their job.

So, not only did the care chart prevent unnecessary mistakes, but it helped carers see Geoff as a human being with the same capacity for fear and joy as anyone else.

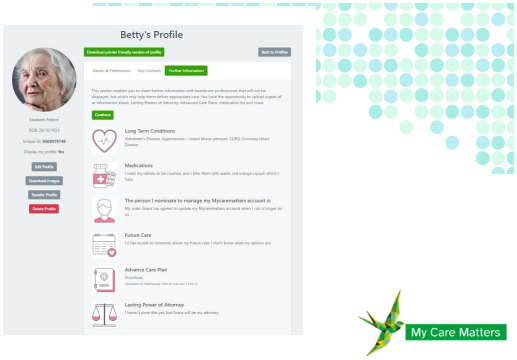
When hospitals became interested I saw how badly they needed something like this as well, something visible to everyone interacting with the person in the bed but when a hospital trialled it and invited me in to show me how well it was working, I saw how little information they'd managed to collect about some of the patients, and how it might take days before they got anything on the chart at all.

It was probably then I realised that this was a task that should not be left until the time it is needed, but done in advance, and ideally by the person themselves. We need to encourage people to create their own profile at a time they still can. How

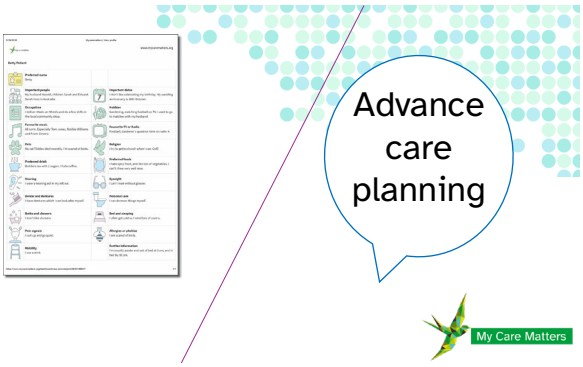
much more empowering that would be, than relying on family members who realise too late they don't know the intricacies of your life and preferences quite as well as they thought they did.

So we developed the Mycarematters profile, a free service where anyone can create a profile of their needs and preferences. It can be accessed by anyone with the person's name, date of birth and Mycarematter's unique code, but actually, a printed copy is still the most reliable way to ensure it gets seen, so we advise people to print it out and take a copy in with them.

It can obviously be updated and reprinted at any time and because it is short there is the option of displaying it on the wall or at the foot of the bed, and has a higher chance of being read than some well meaning but long document that's tucked away in the file.



There's also the option of uploading further information, things that people told us during trials that they would want to share with their medical team.



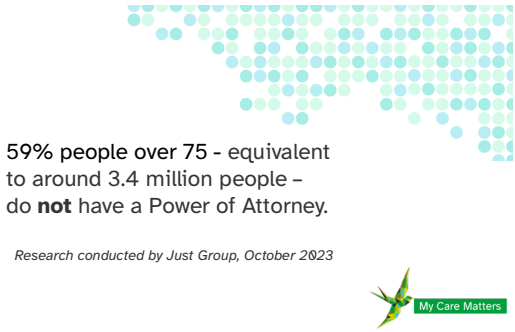
We were trialling the profiles with an NHS Trust in 2018 where they were also looking into why more people were not doing any advance care planning, and we saw how filling in a Mycarematters profile with a patient or their family was a great way of leading the subject on to what they might want in the future.

We ran some workshops with that Trust and did 2 years further research to understand the barriers preventing people from making plans for their future care and end of life.

I'm sure that none of these will surprise any of you. We found that people (and by that I mean health and social care professionals just as much as their patients) weren't clear what advance care planning really meant, there was confusion about the different documents, there is this feeling for some people that if you talk

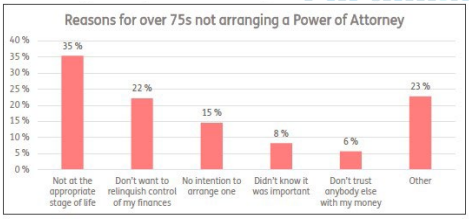
about it it's more likely to happen, and actually, is sitting on someone's hospital bed really the best time to introduce - for the first time - the subject of what they'd like to have happen at the end of their life?

When we ask people what they know about advance care planning, they tend to see it as something that is done when you're dying, and something that a healthcare professional needs to do with you.



It's not surprising therefore, that

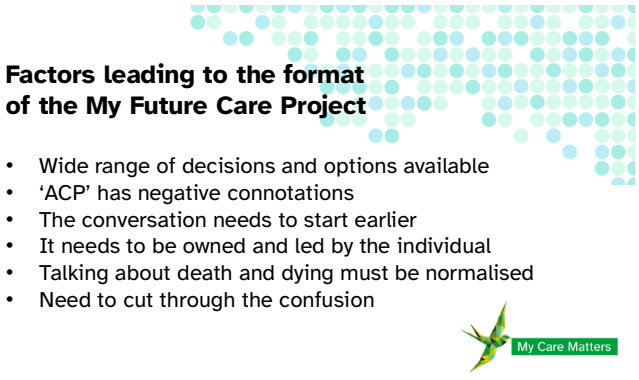
more than half of people over 75 don't have a power of attorney in place and the main reason they give is



because they don't think they've yet reached the age or stage in life where it is necessary!

But none of us knows what's round the corner, so this is not about how old someone is, or their state of health, there are some things that every adult should do to prepare for the future.

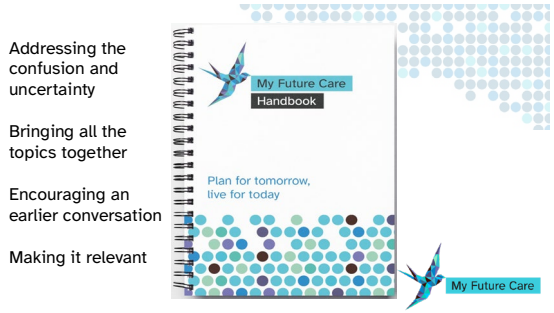
Once people realise that, it's a much easier conversation to have, but it still needs to be relevant.



So these are the factors that influenced the design of the My Future Care project:

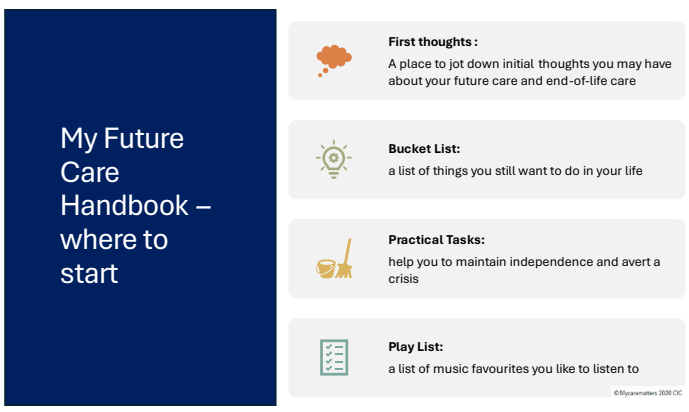
- There are a lot of decisions and options available to us, beyond the needs and preferences we originally identified. So we want to help people live their best life possible right up to the end of their life by making sure they are aware of those decisions and options, and encourage them to put plans in place, to help not only themselves but also whoever is going to advocate for them and then eventually tidy up the loose ends of their life after they've gone.
- Advance Care Planning tends to be equated with **dying** well, but it becomes more relevant to people if we talk about **living** well. Rather than try to change people's perception of advance care planning, we thought we'd have a better chance of achieving our objectives if we talk instead about encouraging people to plan for the future. That can then encompass a much broader set of topics than tends to be considered within traditional ACP.

- This is a conversation that should start much earlier, ideally at a time when the concept of death is still that, just a concept, and not in the middle of a crisis which may or may not be life threatening.
- I've heard people suggest it should even be taught in school. Maybe there's merit in that idea, if only because teenagers might go home and ask if their parents or grandparents have got a Power of Attorney in place, or have thought about the environmental impact of burial vs cremation.
- Anything to bring it out of the shadows. Because we need to normalise conversations around death and dying. It is heartbreaking to hear of even very close families being unable to discuss what a terminal diagnosis actually means, resulting in important things being left unsaid.
- This is not something that should be left until a professional raises it. Yes, they may need to be involved for some aspects, but we need to encourage people to be proactive in thinking about, planning for, and completing the documents for their later life and end-of-life.
- Despite the numerous documents out there, both printed and online, we were unable to find anything that brought it all together. And all those decisions and options I mentioned needed explaining in straightforward jargon-free language we can all understand.



So we developed the My Future Care Handbook. It's a jargon-free walk through of all the topics we should be considering as we approach later life.

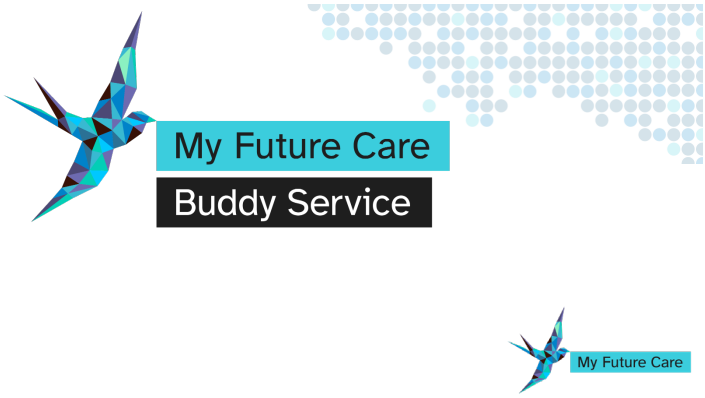
It was a deliberate decision to print it, and not just create another resource online because there are still almost 6 million people over 65 who are not comfortable with or are unable to use the internet. But we do provide QR codes that link to online resources for people who are willing and able to go online. We would certainly encourage people to store documents online where those facilities exist and in areas where organisations like the ambulance service can access them.



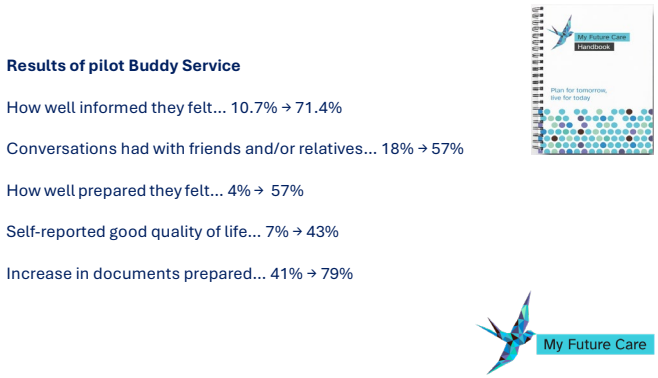
One of the challenges is how to get people to make a start, so we offer a number of ways in, all of which gently encourage people to start thinking about what matters to them, and then to go on to consider the wider picture.

Nevertheless, soon after we launched the Handbook we recognised, as simple and easy as it is to use, many

people need some encouragement to make a start, perhaps they need help to remove the barriers that are preventing them from getting on with it, and over the last 4 years we've seen how much more likely people are to get their plans in place if they are offered some level of support.



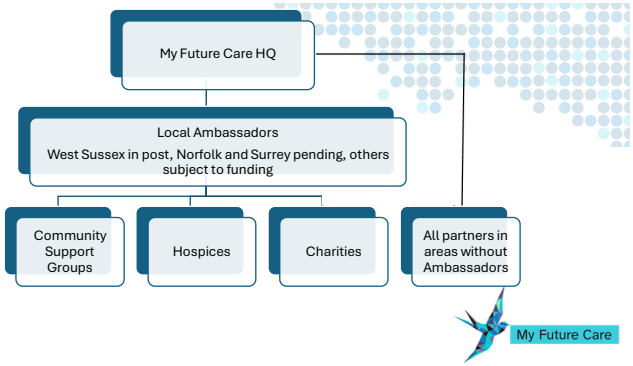
So we initially trained our own volunteers to support people to think through their priorities, develop an action plan and see it through, using the Handbook as a source of information and structure for the conversation… and because this was during Covid our only option was to support people remotely, via video or phone call.



We ran a pilot and recorded some excellent outcomes. In a nutshell, we significantly improved people's level of feeling well informed, the number of conversations that had taken place with friends or relatives, how prepared they felt, their quality of life and the number of documents prepared.

But there was no point in us building up a team of volunteers when there are so many fabulous organisations already using volunteers to support the people in their communities, so since 2021 we have focused instead on partnering with organisations in the community whose clients or members would benefit from making plans for later life.

The My Future Care project is a national programme but we follow a 'think national act local' philosophy. So we provide the training, Handbooks and ongoing support to community organisations around the country who then go on to help their members or clients make their future plans, and they do that in whatever way works best for them and their community, whether 1-2-1s, running group sessions, as part of a weekly or monthly meetup, drop ins or any combination of those.



To facilitate that approach we recently introduced a model of having local Ambassadors who are familiar with their local network and can support our partner organisations at local level.

So, let me stop sharing... and introduce you to Dawn from Henfield who, whenever we have a catch-up, leaves me feeling absolutely exhausted just listening to all the things they've got going on. Dawn, can you explain what you've been doing to encourage and support people to make plans for the future in your area...

Good morning. My name is Dawn. So I'm here actually live from the Henfield Computer Club this morning, which if you look at my background, I'm sitting in a little corridor of cupboards. because everything is going on literally next door. So the Henfield Computer Club is also a community service as part of the Henfield Community Partnership. So that's our overarching umbrella. We do a lot of sort of networking in the Horsham district and that's where we came across Zoe and it resonated very much with me her story because at the age of 29 I found out my mum was diagnosed with dementia and she was only 57. So it really came as a bolt out the blue. There was no warning, nothing.

So there was no preparation, nothing like this fabulous handbook there is today. So I had a sort of vested personal interest and then of course with the audience we have and in Henfield 30% of our community residents are over 65. So it was just a natural sort of opportunity to introduce this to our club.

The computer club runs on a weekly basis on a Wednesday from 10 until 12. We have about 168 different members that come along and when they they've got anything that's sort of technical, mobile device, you know, how to do something online, anything at all and then every other month we'll do a presentation to them. So we thought this would fit really well.

So we did a presentation to introduce the concept. We did a snippet of Zoe's fantastic online video, showed them the handbook and talked about it in a sort of very light-hearted way. Then we broke down into much smaller workshops so that people that were interested in finding out a little bit more because it is quite a scary subject for a lot, came along and again very light-hearted, we could talk about some practical examples going through the fantastic checklist on page 5 and 12 of where we could possibly start how do we have these conversations. The beauty of the workshop meant that they could chat to each other. So although some didn't feel it was a subject they could talk about at home very easily, they found that actually they could talk to strangers more easily.

So we got a team of our mentors trained with as buddies with Zoe and Cath and as a result of that we were then able to offer one-to-one service. So we did more workshops got more people interested in the handbooks could talk about specifics with them then on a one-to-one. Now, sometimes we can do that here at the computer club if it's we can find a sort of quiet corner to do that or we would do it as home visits or they'd come to our house and chat.

And because we know them, we all felt very comfortable and very safe and because we built that trust up previously through the club, they felt very happy talking to us about that. So, we've reached a lot of people. We've done over 90 handbooks so far through the computer club and also another group I'm involved with the self-help group.

While we were doing this and it was it was sort of obviously progressing so well and it's lovely to be able to talk to the community. We wanted to be able to share this wider. So we also went along to the older people's forum who came to Henfield back in April and also the community partnership forum in April and started sharing some of the examples and some of the sort of quick wins and stories of how we'd introduce this and they too have become incredibly interested. So again, we've passed those on to Zoe to again be able to then hopefully share and continue to escalate the great work.

The feedback we've had from a lot of our members has just been wonderful. The difference it's made and I think the biggest thing that stands out for us is they just didn't know there was sort of so much so many opportunities. They thought, I've got a will in place. That's it. Job done. Big tick without realising there's so much more to do. And again, this element of if you plan, you can then not worry about it and really concentrate on on enjoying life. And if you looked at the room next door to me, you will see probably the average age in there today is about 84. So they are living life to the full and enjoying getting to use to their technology too.

Thank you Dawn! To sum up, our training and ongoing support is free to anyone in a position to support people to make plans for later life. Handbooks are available to buy individually or in bulk, we can currently provide them free in West Sussex, and we can offer organisations the opportunity to add their own branding to the Handbook if they wish.

I should also mention that we're currently piloting a 5 week ageing well programme, aimed at anyone over 65 or with moderate frailty, to raise awareness of the practical things people can do like exercise, eat well, get their medication reviewed as well of course as getting plans in place.

For further information on that and anything else we've mentioned, our email address is info@mycarematters.org and you can also read more about My Future Care on the project website: myfuturecare.org.