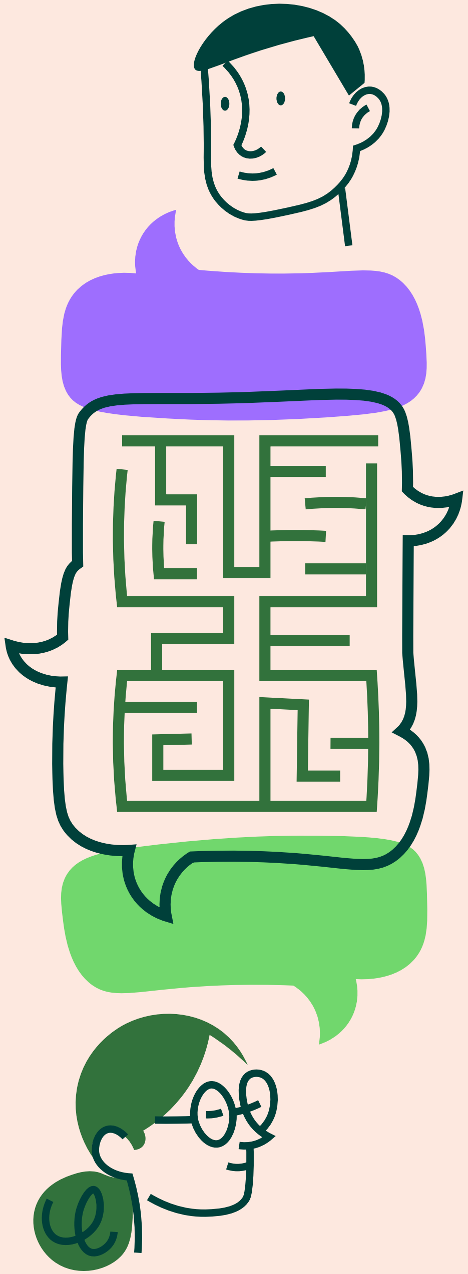
Compassion in Dying.
Your end of life. Your way.

Peer support, power and personalisation

A pilot project for people with a serious or terminal diagnosis



June 2023

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Summary

The affirmation of someone saying, "Ah yes, that happened to me too", is so important. Otherwise, you feel so alone.

In February 2021, Compassion in Dying launched the Peer Navigator Service. The project supported people with a life-changing or terminal diagnosis to improve their physical and emotional wellbeing by sharing knowledge, experience and practical help from a 'peer'. The service:

- Provided an opportunity for people to consider their worries and priorities with someone who had been through a similar experience;
- gave practical support to enable people to make decisions about their treatment and care; and
- helped them to navigate and access local and national support.

The service was operational for 17 months between February 2021 and September 2022, supported 91 people, and had 13 established referral routes including condition-specific charities and social prescribing networks.

Through an independent academic evaluation and service monitoring, we have gathered experiences and insights from the people we supported. These paint a rich picture of the reality of navigating the healthcare system when living with a life-changing or terminal diagnosis.

Communicating in appointments and making treatment decisions is challenging for many

We learnt, unsurprisingly, that even when people have been given a diagnosis and have an ongoing relationship with their doctor, there are still times when they don't feel confident and in control. People very often need support to communicate with their healthcare team, understand their options and make decisions that are right for them.

People told us clearly that often they do not know how to prepare for appointments, cannot find and absorb relevant information and struggle to prioritise their own concerns due to having to deal with so much at once.

Many people experience a power imbalance between them and their healthcare team, which means they don't feel able to ask the questions they need to ask or cannot advocate for themselves and subsequently, without support, cannot make decisions that are right for them about treatment.

A peer can help level a power imbalance and improve wellbeing

The Peer Navigator Service delivered tangible benefits for people, particularly those with a new diagnosis of serious illness. We found that a peer – someone who has walked in similar shoes to you, who is not in a position of power like clinicians are – can help people to address multiple issues to do with their health and wellbeing in a way that professionals cannot.

After receiving support from the Peer Navigator, people told us they:

- felt less emotionally overwhelmed, calmer and more positive;
- were able to communicate more effectively with their healthcare team;
- felt relief at being able to raise issues and ask questions that they had not been able to ask of anyone else;
- appreciated holistic support from someone who was independent;
- accessed new and useful information and resources;
- were more willing to try self-management suggestions because the Peer Navigator had personal experience of some of the same issues and her suggestions were based on things that had worked well for her;
- felt more at ease speaking with someone who had had similar experiences rather than a professional; and
- felt supported through the initial difficult stages of finding out they had a serious illness.

Recommendations summary

- Information needs to be developed nationally to help people prepare for consultant appointments. This should communicate that you can prepare for appointments, it's OK to ask questions and it's helpful to talk about what matters to you.
- NHS England and Integrated Care Boards should consider peer support as an effective way to help people take part in shared decision-making when information alone is not enough.
- Care standards and clinical guidelines should include 'preparing for your appointment' information and a referral to peer support services, where available, as essential pre-appointment preparation.
- Further research should be conducted on power imbalances that exist between clinicians and people, including the role that levelling this imbalance can play in facilitating shared decision-making.

80% of callers reported feeling better able to communicate with their healthcare team about their health, treatment options and managing their condition

100% said they felt more confident in managing the symptoms of their condition

80% of callers reported feeling better informed about specific support available for their condition

70% said their emotional wellbeing had improved

80% said they felt less alone

The Peer Navigator Service

Our Peer Navigator, Hina Sharma, had a serious and life-changing diagnosis in December 2019 of a subarachnoid haemorrhage (a brain bleed). She used her experience to support others facing a similar situation of complex treatment decisions and the challenges this brings. The support the Peer Navigator service offered complemented both the clinical care people received from their healthcare team and the practical information Compassion in Dying provided on planning for the end of life.

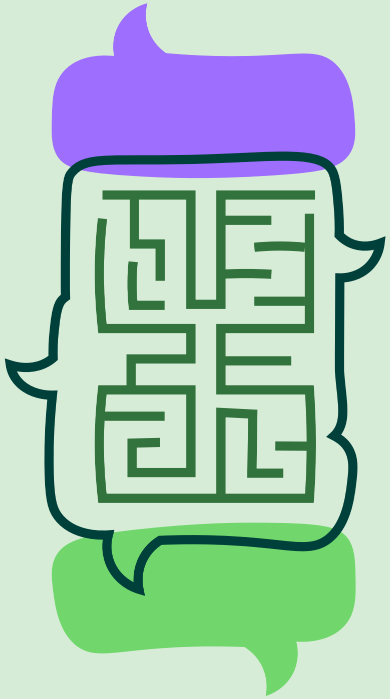
The Peer Navigator Service:

- **provided an opportunity for people to discuss their worries, hopes and frustrations with someone who has been through a similar experience;**
- **gave practical support on how to get the information they need to be able to make decisions about treatment and care; and**
- **enabled them to navigate and access local and national support.**

Multiple, overlapping needs

The Peer Navigator Service supported people who often had multiple needs, which they struggled to identify and prioritise. These included anxiety, fatigue, uncertainty about how to access or evaluate relevant information, difficulties in communicating with doctors and healthcare providers, difficulties understanding treatment options and making decisions, and challenges in talking about their diagnosis or condition with family, friends and employers.

Many people had recently received a new diagnosis. This was described as ‘a busy, stressful time’ where people have ‘lots of issues’ and unanswered questions. Similar pressures were experienced when awaiting a key consultant appointment about illness progression or when facing important treatment decisions, which many people had to make.



People’s experiences of consultant appointments, talking to doctors and making decisions

People told us they found it hard to communicate effectively with their healthcare team and make the most of appointments. Specifically, many people needed support to:

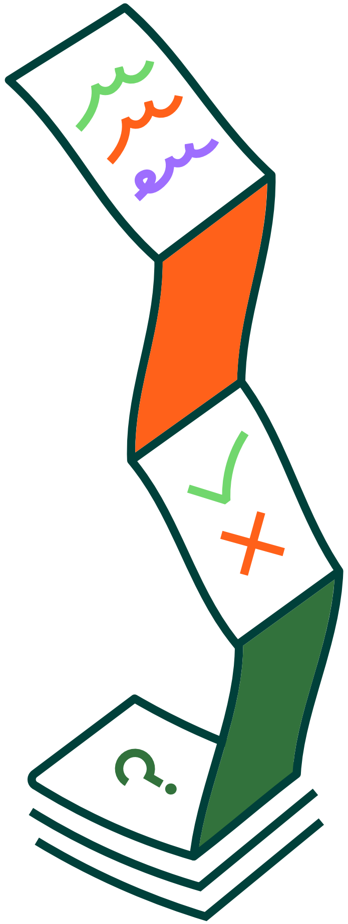
- know that they can prepare for appointments and that it’s ok to ask questions of their healthcare team
- identify their multiple and often overlapping concerns and prioritise their worries and goals
- know what questions to ask
- feel confident and able to ask these questions

Before an appointment

People did not know how to prepare for appointments or even that they could. Many people were awaiting a first consultant appointment following their diagnosis and most had not considered that an appointment could be something they could prepare for, let alone how they could prepare in order to get the most from the meeting.

Consequently, many people approached medical appointments feeling nervous or concerned. People generally had not considered whether they had specific aims or goals and sometimes expressed uncertainty about what an appointment might cover. In some cases it was clear that there was a range of treatment options that might be available to the person which they were unaware of and therefore not able to consider.

People’s experiences of consultant appointments, talking to doctors and making decisions



During an appointment

People found it hard to ask questions of their doctor because they experienced a power imbalance or because they felt overwhelmed in the moment.

The majority of the people we supported did not feel confident asking their doctor questions or asserting their opinions. For many this was due to the power imbalance that existed between them and their doctor. Although people did not use the phrase ‘power imbalance’ when describing their relationship with their doctor, it was clear that the natural disparity between levels of technical knowledge, the fact that people often felt confused, stressed and vulnerable, and people’s fears of ‘upsetting’ or ‘offending’ their doctor meant that such an imbalance existed.

People often felt overwhelmed by the volume of information doctors offered. This information overload meant that for many, they were unable to absorb the key information they needed to know in order to make complex treatment decisions for themselves. And the use of jargon and abbreviations by their healthcare team furthered the feeling of overwhelm for many.

Some people told us that asking questions and feeling confident in a conversation was not easy at a point in their lives when they are feeling overwhelmed, confused or vulnerable.

> **Now I’m terminal I’m worried my oncologist won’t make the same effort – how would I even speak up to challenge that?**

> **Usually it feels like my doctor has the bats, the balls, the lot and I’m not even asked to play. At least now [after support from the Peer Navigator] I have some questions to help me have a conversation rather than being talked to.**

People's experiences of consultant appointments, talking to doctors and making decisions

People often told us they could not think of all the things they wanted to ask in the moment while simultaneously taking on board so much new information, all within the context of a 20 to 40 minute appointment. Some said they did not feel comfortable asking questions because they were worried it was not appropriate or polite. Others also said they felt they were being a nuisance if they asked too many questions.

> **Mr P wanted to know how long he was likely to live, but was very reluctant to ask his consultant this question because he thought it was "indelicate to ask that."**

After an appointment

Following an appointment with their doctor, people frequently said they had unanswered questions and did not have all their concerns addressed. As a consequence of this they continued to worry, and this often added to their feelings of uncertainty and anxiety. Importantly it led to some people failing to come to terms with their condition or utilising self-management techniques as effectively as they could otherwise have done.

There is a cumulative effect to this anxiety, as people often feel they need to use time in their next appointment to clarify things from their previous appointment, reducing the time they have to discuss any new concerns that have arisen.

There was also a concern from people that there was often no way to clarify information or ask follow up questions after an appointment, until the next appointment which was sometimes weeks away. For many, they needed time to process the information they had been given before they were ready to ask questions and discuss next steps, but unfortunately most people did not have an easy way to communicate with their doctor after the appointment had ended. This meant people were left with unanswered questions in a 'limbo period' increasing their anxiety and dramatically affecting their emotional well-being.

A peer-led approach: identifying needs, preparing questions and levelling power imbalances

Supporting people to understand, identify and address their overlapping needs and concerns

The Peer Navigator would support people, over a series of conversations, to crystallise what they most wanted to know from their doctor. This involved helping them to consider their priorities in terms of:

- their life and what matters most
- living with their condition
- any treatment options available

> **Drawing up questions based on what's most important was so useful. So far previously, it felt like I've had little choice and have just been told what needs to happen next.**

To do this, the Peer Navigator often discussed with people what they knew about their condition and explored with them the sorts of things that they wanted to gain from the appointment or that they thought the consultant might raise. The Peer Navigator described this as helping people to *'break down the information they have and to think through what they are most worried about and what their priorities are'.*

Together we wrote a list of her symptoms and their severity so she did not have to repeat these with everyone involved in her care, especially as she had issues of fatigue. I also researched and shared questions the care team were likely to ask so she was prepared.

Preparing questions

In the course of these conversations with service users, the Peer Navigator often wrote things down that they later sent to the person by email, so that they had a list of the questions they had identified that they could refer to. She also helped people rehearse their most important questions, to help them find the right words and feel confident.

When you see an oncologist, he really knows the score, seen hundreds of cases before, and you are on your own, so having some ideas of what to ask him is very powerful. It was one of the reasons we came out of that meeting [with the consultant] feeling so positive.

One person we supported said that by knowing about some of the possible treatment options for his condition and preparing questions in advance he *'could actually talk'* during his appointment and *'not just sit listening'*, which he felt was empowering.

An open-ended, exploratory, iterative approach

The Peer Navigator helped people sift through and prioritise their concerns, as well as reflect on what information and support had been most useful to them.

As part of our external evaluation, we spoke with people who used the service and professionals who referred into it. One of the social prescribers who referred people to the service said that the way she describes this exploratory approach to people she refers is *'helping people come to terms with dealing with the effects of a long-term condition.'*

This personalised, responsive approach allowed people to voice all sorts of inter-related worries and concerns, some of which they had not been able to bring up elsewhere. For example questions they did not feel comfortable asking their doctor and personal issues such as how to talk about their diagnosis with families, friends and employers.

This approach also helped people to self-identify previously unrecognised issues they were facing, which they were not aware they could obtain help with. The Peer Navigator called this *'the unknown unknown.'* The lack of awareness of available support and services was a common theme for many.

The service provided support that was not time-limited, ending by mutual agreement, with an 'open door' policy for anyone who wanted to get back in touch later. People reported that being able to address issues in their own time helped them feel more in control, at a point in their lives when they did not feel in control of their health or lives in general. Notably, Social Prescribers found that being able to refer someone to a service that did not have a set time limit was hugely beneficial for the people they referred and gave them (the Social Prescriber) peace of mind knowing their patient would be well supported.

How peer support builds trust

Support from someone who has walked in similar shoes to you builds trust and makes people more likely to accept support

The healthcare professionals we interviewed thought that talking to clinicians is commonly difficult for lots of people, and this was also reflected in the accounts of the people we supported. Conversely, we found that being able to speak with someone who has experienced something similar to the person being supported builds trust, makes people feel more comfortable and able to speak openly and accept support.

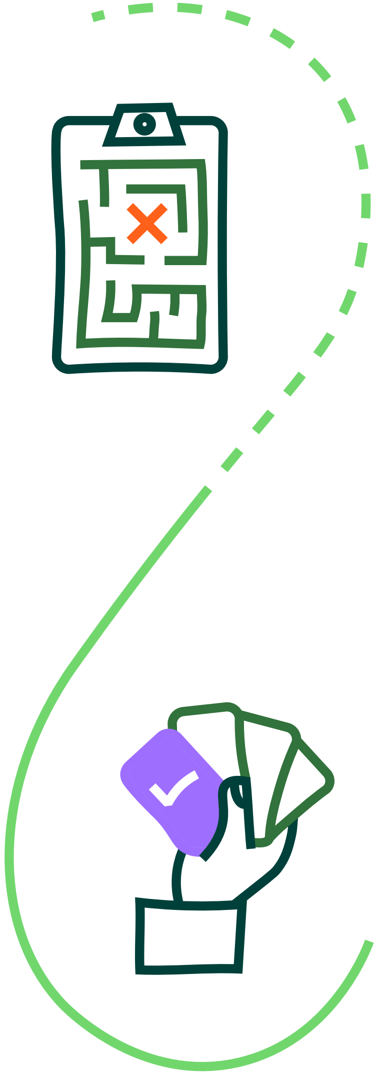
> She introduced herself as, 'I am not a clinician, this is just me doing this.' That made me feel more comfortable with her and able to speak more openly. I would have been more cautious speaking to someone more official .

The presence of a 'peer' was one of the most successful and appreciated aspects of the service. For some people, the fact that the Peer Navigator had her own experiences of dealing with serious illness helped to establish a bond.

> There were aspects of my condition that she understood having experienced them herself. That established empathy between us, a fellow feeling.

> She'd experienced that 'gut in throat' moment or 'gut in mouth' moment, you know, and that felt good because I was able to talk on a level with someone who had some understanding.

How peer support builds trust



This shared experience was extremely important for people who had been newly diagnosed, helping them to feel validated and less alone and enabling them to have a broader perspective on their situation.

It also meant that people felt less need to explain themselves, especially concerning the psychological and emotional impacts of receiving a serious illness diagnosis.

> The affirmation of someone saying "ah yes, that happened to me too" is so important, that part of the service is so important. Otherwise, you feel so alone.

> I found speaking to [the Peer Navigator], who has been through the mill herself, really helpful in putting things into perspective.

> There were some things that I said, and I can't remember exactly what they were, but she "got it". It was a relief to not have to explain side effects of treatment and to not have to explain how all-consuming and how frightening it is.

Accessing holistic support from someone independent enabled people to feel more confident in the help they were offered

People were more willing to try self-management suggestions from the Peer Navigator because she had personal experience of some of the same issues and her suggestions were based on things that had worked well for her. For example one service user said it was really helpful being guided by someone who has *'been there.'* At the same time, the personalised and responsive approach adopted reassured people that the information and suggestions the Peer Navigator gave were tailored and relevant to their specific concerns and circumstances.

People valued being able to speak openly about a range of concerns and challenges with someone who was neutral and independent.

> When you talk to people at work, they are focused on what that means for them within the organisation. When you talk to family members, they're still carrying their own narrative of what that situation was, the bad memories it brings up for them. Talking to someone who was not involved emotionally was great because we were able to have discussions and, you know, share.

Learning for future peer support services

Despite the benefits to the people supported, there were also challenges in developing and delivering the service. For others considering delivering peer support for people at the end of life or living with a life-changing diagnosis, there are key considerations to ensure the success of such a service.

Establishing effective referral partnerships requires a well-defined service offer

The Peer Navigator Service had thirteen established referral routes including disease-specific charities and social prescribing networks. These relationships were built over time using evidence from the service, as it was delivered. However, generating referral routes proved difficult.

In part, we believe this was due to the open-ended scope of the Peer Navigator Service. From the outset, we deliberately did not define or limit the types of needs and issues that people could talk to us about, other than explaining that they could discuss their worries, hopes and frustrations; get practical support on how to get the information they need to be able to make decisions about treatment and care; and get help to understand and access local and national support. This strategy enabled us to hear and understand the broad problems that people with a serious and terminal diagnosis in the UK are facing. It also allowed us to learn what types of support are best suited to peer support in this space.

However, it had an impact on the ability of people to instantly understand the purpose of the service. Stakeholders we spoke to initially reported they sometimes struggled to know who was appropriate to refer to us. Clarifying who the service was for and building relationships with referrers was time consuming.

It became clear that providing support to people to prepare for appointments, prioritise their concerns and goals, ask questions and communicate with their healthcare team was the most needed and impactful aspect of the service.

Learning for future peer support services

The breadth and depth of the support needed takes time to deliver

The breadth and depth of support that the Peer Navigator was able to provide was resource intensive due to the time taken to support each person. However, we know that the open nature of the service had tangible benefits, including preventing people feeling immediately overwhelmed. It allowed people to focus on what was most important at that time and address other needs afterwards. This approach was also found to help people feel both safe and in control.

Being a "peer" is not an easy role

The Peer Navigator's empathy, and the assurance of being able to speak with someone who "gets it", was consistently appreciated by the callers. However, despite being committed to using her experiences to support others, re-living difficult life events on a daily basis was challenging. The emotional investment needed to support others must not be underestimated and must be supported. Compassion in Dying provides specialist counselling support to all staff including the Peer Navigator and this should be a key consideration in developing similar services.

Next steps

The value of the Peer Navigator Service cannot be disputed. Individuals who received support reported feeling more confident, better informed and less alone. People were more able to come to terms with their diagnosis, ask questions in appointments and make decisions about their treatment and care. It improved emotional wellbeing and people's treatment decisions were more likely to align with their personal goals.

People told us that the disparity between levels of knowledge, and of confidence, can create a power imbalance between them and their doctor. This power imbalance causes unintentional harm as, because of it, people struggle to ask questions, understand their options and make decisions that are right for them.

This pilot project has demonstrated a clear and urgent need to invest in support to enable people with a serious diagnosis to prepare for appointments and communicate with their healthcare team. We believe that clear information on how to prepare, with the additional option of peer support for those who need it, would help to achieve this. Specifically:

- Clear information needs to be developed nationally to help people with a new serious diagnosis prepare for consultant appointments. This should communicate that appointments are something you can prepare for, it's OK to ask questions and it's helpful to talk about what matters to you.
- For many, information alone is not enough. NHS England and Integrated Care Boards should therefore also consider peer support as an effective way to help people meaningfully take part in shared decision-making.
- Care standards and clinical guidelines should include the above 'preparing for your appointment' information along with an optional referral to peer support services, where available, as essential pre-appointment preparation.
- Further research should be conducted on power imbalances that exist between clinicians and people who have had a diagnosis of a serious illness, including the role that levelling this imbalance can play in facilitating shared decision-making.

This report is a summary of the evaluation undertaken on the impact of peer support for people with a new, serious or terminal diagnosis. The full academic report is available on request.

Compassion
in Dying.

Your end of life. Your way.

At Compassion in Dying, we want people to be in control of their end-of-life decisions because there is no-one better to make them.

We champion everyone's right to make informed decisions. Free of cost and free of judgement.

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