

# Mac Voice

For Macmillan Professionals | Issue 94 | Autumn 2020

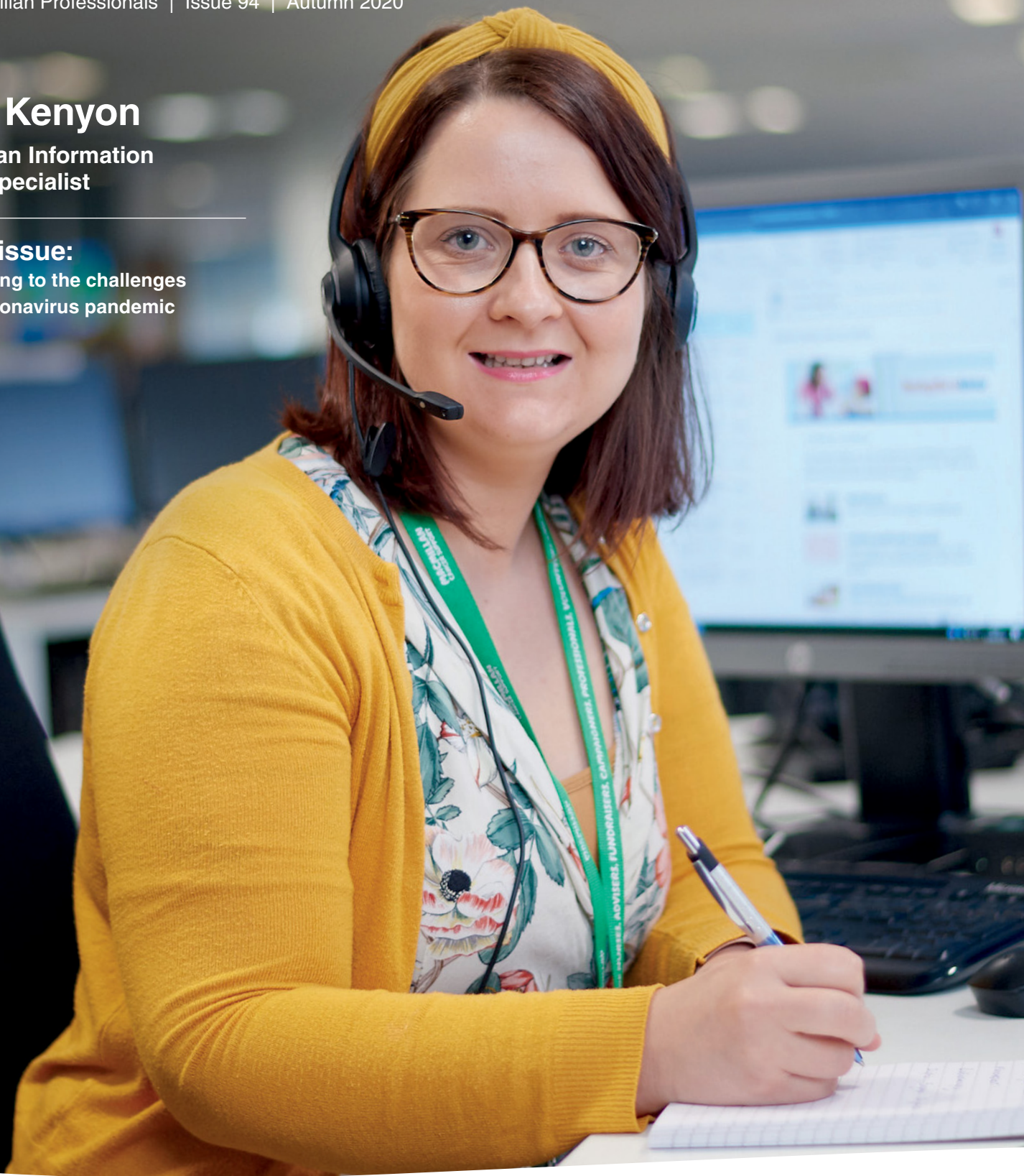
## Amy Kenyon

Macmillan Information  
Nurse Specialist

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### In this issue:

Responding to the challenges  
of the coronavirus pandemic



**MACMILLAN**  
CANCER SUPPORT

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## Welcome

Welcome to the Autumn 2020 edition of *Mac Voice*.

Healthcare professionals continue to face many challenges as a result of the coronavirus (COVID-19) pandemic. You can read about how Macmillan has responded to the crisis in a message from our CEO Lynda Thomas, get an update on how fundraising has changed for the organisation and find out what it takes to develop information in a fast-changing environment.

This issue features a Q&A with Amy Kenyon, Macmillan Information Nurse Specialist, who talks about the highlights and challenges of her role on the Macmillan Support Line, as well as the impact of COVID-19. Find out more on page 10.

We showcase the work of several individuals and Trusts during the pandemic, including innovative ways of working in Liverpool, Crewe, Northern Ireland and Barking, Havering and Redbridge. We also hear about the role of a palliative care chaplain in Antrim Hospital, and the importance of spiritual care.

Also featured are a pilot project providing cancer information and support for the deaf community and an insight into the financial barriers for patients with no recourse to public funds.

Some of the photos in this issue were taken before the government introduced the rules on social distancing. Due to the impact of the pandemic, there will be no Winter issue of *Mac Voice*. The next magazine will be published in March 2021.

In the meantime, you can keep up-to-date with the latest news from Macmillan at [macmillan.org.uk/about-us/health-professionals](http://macmillan.org.uk/about-us/health-professionals)



**Elissia Albertella-Howell**  
Managing Editor







## News

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## Our response to the coronavirus pandemic

Macmillan Chief Executive Lynda Thomas on how we are adapting as an organisation to continue supporting people with cancer.

The year has been difficult and continues to be so. My thoughts have been with you as you've worked tirelessly to support your patients. Some of you will have been working as well as having additional caring responsibilities and many may have had to isolate with symptoms, while supporting family, friends and colleagues, or may have sadly lost loved ones. Thank you for your resilience and commitment in the face of this adversity.

Every day I'm heartened by stories of Macmillan helping people, but there are still thousands of people with cancer who may be feeling isolated, forgotten or are living in fear. The scale of possible long-term damage caused by coronavirus on the health of our nation and to the lives of people living with cancer cannot be ignored. That is why our 'Forgotten C' campaign will continue to be our influencing priority for the rest of the year; to ensure governments prioritise the recovery of disrupted cancer services so people living with cancer have access to essential NHS cancer services including diagnosis, treatment and end of life care.

Alongside this campaign, our focus has been to maintain our support services for people with cancer and their loved ones. I'm proud we have been able to keep our support line open seven

days a week and have launched a number of new services to support people with cancer, which you can read about on page 7.

In some ways, the pandemic has brought out the best in Macmillan. We have acted quickly and collaboratively to find new ways to support people living with cancer. However, in common with other charities, we have seen a substantial decline in our income and we have needed to make some very difficult decisions. The first of these was early on when we had to stop many of the grants to support new and existing Macmillan services. And recently you will have seen the devastating announcement about the redundancies that we need to make in order to be able to continue to provide vital frontline cancer services.

We don't know for definite how coronavirus will continue to impact people living with cancer, the NHS or Macmillan. What we do know is that we need to take action now in order to step up to the challenge that we face and ensure that Macmillan can continue to help people living with cancer. This will include supporting you where we can as I recognise you, as professionals, need our support more than ever. I hope you have been able to make use of our coronavirus information hub which provides

information and the latest guidance on cancer and COVID-19, as well as a wide range of emotional support resources and links to our Employee Assistance Programme. You can find out more at [macmillan.org.uk/professionals-wellbeing-support](https://macmillan.org.uk/professionals-wellbeing-support)

Finally, I would like to update you on inclusivity at Macmillan. The killing of George Floyd has brought to the fore the huge systematic inequalities and prejudice that are faced by the Black community not only in the US but also in the UK. These events made me reflect that Macmillan is still not where it should be in relation to the inclusivity agenda. This is now firmly an organisational priority. There is no denying that we have a lot of work to do, but this starts now.

We have made **five commitments** to make long-lasting change:

1. We will make tackling inequality – including racial inequality – a core goal for every Macmillan service.
2. We will use our voice to tackle inequalities in services and support for people living with cancer.
3. We will promote diversity and inclusion in the health care workforce.
4. Our brand will be more representative of society.
5. We will place diversity and inclusion at the heart of our organisation.

Thank you for the work you are doing to make sure we are continuing to deliver for people with cancer. Recent months have been far from easy and this is likely to continue for some time. I ask that you please continue to be kind to yourself and your colleagues.



**Lynda Thomas**  
CEO Macmillan Cancer Support

## In brief

### Free Will Service wins award

Macmillan has won an award for Legacy Campaign of the Year 2020 from the Institute of Fundraising for our Free Will Service. The annual National Fundraising Awards aim to recognise and promote best fundraising practice in the charity sector. We launched our Free Will Service in September 2019. This was supported by a media and digital marketing campaign highlighting the importance of leaving charitable gifts in wills. There were 706 pledges last year (160% of our target), resulting in £11,046,810 of future estimated income for our work. It is easy to register for the service at [macmillan.org.uk/freewill](https://macmillan.org.uk/freewill) or by calling **0300 1000 200**.

### Revised guidance on lymphoedema services

Updated guidance has been published for commissioners to improve the quality of life for people with lymphoedema in London. This was developed by the Transforming Cancer Services Team and the London Lymphoedema Community of Practice. The revised guidance identifies how services are currently commissioned in London and where improvements are needed. It also addresses education and training needs for the wider workforce. Read *Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer 2020* at [healthylondon.org/resource/commissioning-guidance-lymphoedema](https://healthylondon.org/resource/commissioning-guidance-lymphoedema)

### Macmillan awarded information quality mark

Macmillan has been awarded the new UK quality mark for health information. The Patient Information Forum (PIF) launched the PIF TICK (Trusted Information Creator Kitemark) to replace the Information Standard. To be awarded the PIF TICK, an organisation is assessed and must meet 10 criteria. These include using reliable, up-to-date evidence, writing in plain English and involving patients to develop health information. Visit [pifonline.org.uk/pif-tick](https://pifonline.org.uk/pif-tick)




## Update on the Macmillan Professionals Conference and Awards

We've made the difficult decision to postpone this year's Macmillan Professionals Conference and Awards. Even though we will not be running face-to-face events this year, we want to ensure you feel connected and supported during this time.

We have developed a series of virtual best practice forums, centred around specific topic areas, aimed at providing you with opportunities to learn and share best practice. We ran three successful events in August and September and plan to continue running these virtual forums over the coming months. Keep up to date with new session dates at [cvent.me/DIq9br](https://cvent.me/DIq9br)

As well as our best practice forums, we plan to continue developing our virtual events programme throughout the year. Keep your eyes peeled for emails over the next few months for updates.

If you have any questions for the team, please do contact us at [eventsadmin@macmillan.org.uk](mailto:eventsadmin@macmillan.org.uk) 

## What's coming up?

### October

#### Breast Cancer Awareness Month

[wearitpink.org](https://wearitpink.org)

#### National Braille Week

5-11 October

[royalblind.org](https://royalblind.org)

#### World Mental Health Day

10 October

[who.int](https://who.int)

#### World Hospice and Palliative Care Day

10 October

[thewhpca.org/about](https://thewhpca.org/about)

### November

#### Pancreatic Cancer Awareness Month

[pancreaticcanceraction.org](https://pancreaticcanceraction.org)

#### Lung Cancer Awareness Month

[roycastle.org](https://roycastle.org)

#### Mouth Cancer Action Month

[mouthcancerfoundation.org](https://mouthcancerfoundation.org) and [dentalhealth.org](https://dentalhealth.org)

#### International Stress Awareness Week

2-6 November

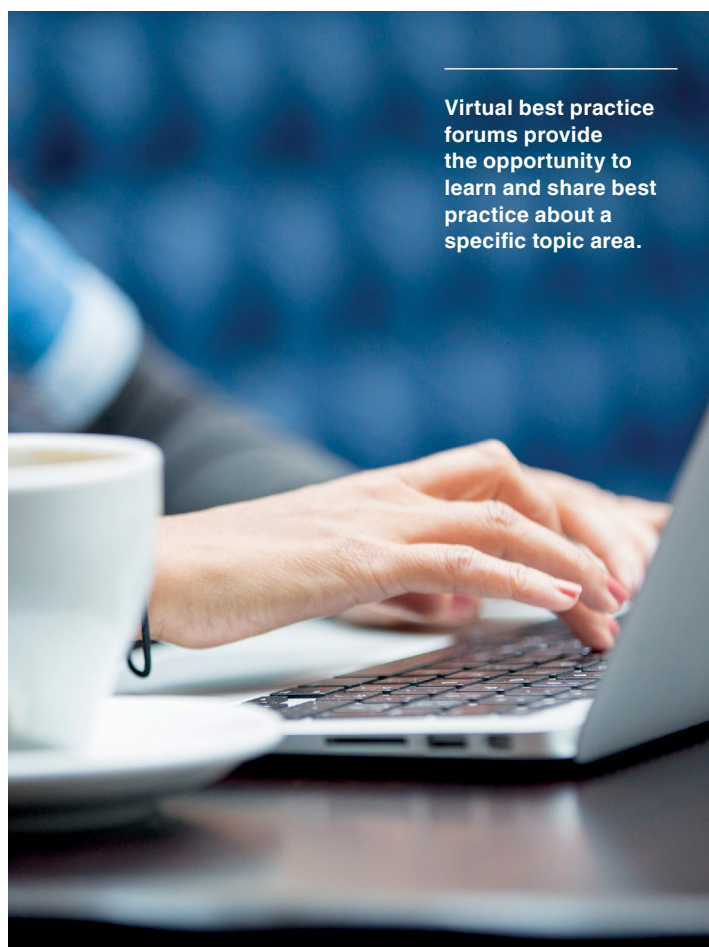
[isma.org.uk](https://isma.org.uk)

### December

#### International Day of Persons with Disabilities

3 December

[idpwd.org](https://idpwd.org)





## How Macmillan is responding to the coronavirus pandemic

How Macmillan is responding to the changing needs of people living with cancer during the coronavirus (COVID-19) pandemic.

In these difficult times, it is more important than ever that Macmillan communicates effectively with people living with cancer. Our strategy focuses on making sure that our services reach people living with cancer at the times when they need us most.

We have developed and are constantly updating the content on our coronavirus information hub, in line with the government's coronavirus (COVID-19) guidelines. This includes information for people living with cancer, carers, those who are shielding or self-isolating and healthcare professionals. See [macmillan.org.uk/coronavirus](https://macmillan.org.uk/coronavirus)


We have also launched a new influencing campaign to make sure that cancer is not the 'Forgotten C' during the coronavirus crisis. Our campaign calls on UK governments to publish national recovery plans, reduce the treatment backlog and ensure people living with cancer can continue to access treatment safely. Lynda Thomas (CEO) appeared on BBC Breakfast and Good Morning Britain to highlight the emergency campaign.

Many people living with cancer have been feeling isolated over the past few months. We have developed our Telephone Buddy service, which matches an individual with cancer to a trained volunteer buddy. This buddy then provides a weekly phone call for 12 weeks or more, offering emotional support and signposting to other services. See more at [macmillan.org.uk/telephonebuddies](https://macmillan.org.uk/telephonebuddies)

During the pandemic, people living with cancer may be shielding or waiting for treatment that has been delayed. Based on evidence suggesting simple things that people can do to help improve the outcome of their cancer treatment, Macmillan has launched the SafeFit pilot. It is a free, remote service across the UK to help with people's physical and mental wellbeing during this period of uncertainty. The support offered is virtual to maintain social distancing guidelines and, depending on individual needs, can include exercise programmes, nutrition advice and emotional support. Visit [macmillan.org.uk/safefit](https://macmillan.org.uk/safefit)

Macmillan has also launched the coronavirus response fund, which aims to support the delivery of essential cancer care in the UK. A £5 million investment has been announced to support the NHS and make sure that important services reach people living with cancer. The Macmillan UK Partnerships team are allocating the money from a central fund.

One of our corporate partners, Boots, is now offering free virtual Boots Macmillan Beauty Adviser appointments for people living with cancer. These appointments are available as both telephone and video consultations. They can give make-up and skincare advice to help manage any visible effects of cancer treatment.

Coronavirus is having a huge impact on people living with cancer, and we are doing everything possible to develop and meet the growing demand on our services. 



Boots is offering people living with cancer free telephone or video consultations with Boots Macmillan Beauty Advisers.

## Finding new ways to fundraise

Responding to the economic impact of the coronavirus (COVID-19) pandemic requires a more flexible approach to fundraising.

The coronavirus pandemic has made a huge impact on the UK economy. With the charity sector predicting a potential drop in voluntary income of up to 50% in 2020, and the cancellation or postponement of many major fundraising events such as the London Marathon, we have recognised the need to adapt our fundraising strategy urgently.


Ongoing monitoring of consumer trends has shown that public feeling towards charities remains positive. We are very grateful to our fantastic supporters who have continued to fundraise for Macmillan during this difficult time.

At the end of April we launched an emergency appeal, both to raise funds and tell the story of what it is like to be affected by cancer in the middle of the coronavirus crisis. The appeal gained significant media coverage, supported by celebrities such as Fearne Cotton and Martin Clunes. Highlighting Macmillan's role in supporting people with cancer at this time led to a spike in visits to our website, and contributed to us being seen by the public as one of the top 10 charities associated with responding to the crisis. The appeal has raised more than £1.5 million so far.

Earlier in the year we also launched our checking in campaign, calling more than 20,000 supporters to thank them for their ongoing support for Macmillan and let them know about the impact their donation had. This was also an opportunity for us to check in with people affected by cancer, ask how they are doing and signpost to further support.

We have also been working to adapt our regular fundraising activities during 2020 to make sure our advertising feels relevant to the current situation, focusing on our support for people feeling isolated and on our cancer and coronavirus information.

Innovation is key to ensuring that we remain flexible and align ourselves as much as possible with the current experiences of our supporters. We have therefore tested several new fundraising products that people can get involved with from home, using market insight to see what our key audiences are interested in and inspired by. These include the 10-day 5k virtual running events, which have now raised £200,000 and Games Night In, which has reached £500,000 in fundraising.

As we get closer to the end of the year, we have started to evaluate our new products and ways of working. This will help us think about long-term sustainability and how we can emerge from this crisis in a strong position to continue supporting people with cancer. Find out more at [macmillan.org.uk/get-involved](https://macmillan.org.uk/get-involved) 

**Claire Rowney**  
Executive Director of Fundraising,  
Marketing and Communications  
Macmillan Cancer Support

**Innovation is key to ensuring that we remain flexible and align ourselves as much as possible with the current experiences of our supporters.**

**Claire Rowney**  
Executive Director of Fundraising,  
Marketing and Communications



# Macmillan Horizon Centre offers new support services during the coronavirus pandemic

The coronavirus (COVID-19) pandemic challenges information and support centres to find ways of supporting people living with cancer remotely.

During the ongoing coronavirus crisis, the Macmillan Horizon Centre is offering a telephone and virtual support service, helping people living with cancer across Brighton and Sussex.

Although the Horizon Centre is temporarily closed for its usual face-to-face appointments or for drop-in visits, staff have found safe ways to continue to support local people affected by cancer. Through a new service called Horizon Connect, the team are offering emotional, practical and financial support over the phone, by email and online.

Horizon Connect offers the following:

- 45-minute, online group support sessions that give people an opportunity to connect with Horizon Centre staff, as well as other people with similar experiences and concerns. The sessions offer people contact and support in a way that works best for them, whether that is a regular phone call, an online support group or help when they need it.
- Phone support from Information and Support Volunteers from 9am to 4pm. People can get regular support over the phone, or just call for a chat.
- Email support whenever people need it. There is no fixed time, so this may be easier for some people.

This support is really making a difference, with one attendee saying: 'I was in such an awful space at the time I joined online, and during the session I felt held by you, it was as if you were holding my hand and mopping my brow. It really helped me through it'.


The centre is also offering online classes on managing anxiety, pilates, yoga nidra, and acupressure, as well as breathing and cookery workshops. These are all done over Microsoft Teams video conferencing.

One service user thanked the centre for organising and running these sessions: 'I find them very helpful and supportive and am so grateful to you for providing such a valuable and personal resource at a time when I know you are all stretched.'

Working with FareShare and Mhairi Donald, Senior Macmillan Dietitian at the Royal Sussex County Hospital, the Horizon Centre Café is also distributing food packs for patients who struggle to get to the shops. There is also help for people who are discharged without food waiting for them at home.

Geoff Brown, Centre Manager, said: 'Despite the incredibly difficult and uncertain situation every one of us has found ourselves in, we knew how important it was to keep going and to be there for the people who depend on our support, now more than ever.'

Though our doors are temporarily closed and many of us are working alone for everyone's safety, we are very much still here for people affected by cancer in Brighton and surrounding areas.'

The services are open to anyone living in Brighton and the surrounding areas in Sussex. Find more information at [macmillan.org.uk/horizoncentre](https://macmillan.org.uk/horizoncentre) 



## Q&A: Amy Kenyon

### Job title

Macmillan Information Nurse Specialist

### Location

Macmillan Cancer Support, Shipley,  
West Yorkshire

### In post

Since 2018

### Contact

AKenyon@macmillan.org.uk

### When did you join the support line, and why?

I've been on the support line for nearly two years. I've worked in cancer care since I qualified in 2009, and my last role was a clinical nurse specialist for upper gastro-intestinal, pancreas and liver cancers at Leeds Cancer Centre, managing those services as a band 7 nurse.

I've always wanted to work for Macmillan, and I was already doing quite a lot of telephone clinics to prevent people having to travel unnecessarily. Having spent several years in one specialism, I was also interested to step out and learn more about other cancers and what was happening in cancer care more broadly.

### What does working on the support line involve, day to day?

We provide support and guidance to anyone



across the UK affected by cancer, including patients, relatives, carers, friends and people who are worried about cancer. As experienced cancer nurses, we offer this support over the phone and through digital channels such as email and our Online Community, with web chat also coming soon.

We cover all cancer types and a vast range of topics from diagnosis, to tests and treatment and end of life support. People who built up a relationship with us while their loved one was having cancer treatment also often contact us again after that person has died to talk through what happened. So, we support people from the beginning of the pathway right to the end. We also get involved with teaching and mentoring new team members, as well as a range of other projects. And I'm a wellbeing champion, which is keeping me very busy in the current climate. No day is ever the same.

#### **What do you enjoy about the role?**

All the nurses on the support line come from different clinical backgrounds, which I think is what makes this service so unique.

There is so much knowledge within one team and I've learned a lot. It's also a privilege to be able to support people wherever they are in the country, even if they don't have a Macmillan centre nearby – we don't have the postcode lottery issue here. The fact that we are now a seven-days-a-week service is great. I also love working with all the different teams across the organisation, who have completely different areas of expertise.

#### **And what are the challenges?**

Some days the calls are very emotionally challenging, and I'm not sure I was totally prepared for that in the beginning. I think perhaps people see us as more anonymous on the phone and feel comfortable telling us things that we maybe wouldn't have heard in clinics. Increasingly, we are getting a lot of calls from people with mental health issues, both people living with cancer and those who are worried about cancer, and that's challenging because we're not mental health nurses.

#### **How has the coronavirus pandemic impacted your role?**

It's very difficult for people out there with cancer at the moment, and the number of calls has massively increased. People are not getting treatment or are having it postponed, they can't see family and friends, and often only speak to


their healthcare teams over the phone, so it's really tough. We also speak to bereaved people who are not able to grieve in the way they would like, for example with a funeral or seeing family and friends.

Having the support line is a huge asset at this time. That's why we wanted to get back to a seven-days-a-week service, with everyone working from home, as soon as we could. We had the usual teething issues with IT at first, but we got up and running very quickly. However, we're used to being able to check in with each other straight after a call, or reflect on calls on the way home, but now it's much harder to let go of work at the end of the day. We've needed to find new ways of looking after ourselves and supporting each other virtually.

**All the nurses on the support line come from different clinical backgrounds, which I think is what makes this service so unique.**

#### **Has the coronavirus pandemic changed how the support line might work in the future?**

I think it's made us all realise that we can adapt and transition quickly when we need to. It also works well for some people to be more flexible with where they work, so we may look at introducing more home working, as long as there is a balance with face-to-face support for staff. During this time, we've networked virtually and explored new ways of supporting each other which has been really interesting. I've even been hosting Skype meditation sessions for colleagues, which have worked really well. So there are things that we will learn from and hopefully take forward.

We are also currently recruiting more home-based nurses for the support line. This opens up these roles to any nurse, anywhere in the country. This is an exciting opportunity that will change the way we work in the future. 

## Spiritual care and cancer

John Wonnacott, Specialist Palliative Care Chaplain for the Macmillan Unit, Antrim Area Hospital, reflects on the role of a palliative care chaplain, the importance of spiritual care and the impact of the coronavirus (COVID-19) pandemic.

### References

1. Murphy, K & Whorton, B *Chaplaincy and Palliative Care* 2017:104 quoting Rolston
2. Nouwen, H *Out of Solitude: Three Mediations on the Christian Life* 1975
3. Morton, R & McAfee, C *Health Care Chaplaincy Research: A Practical Guide for Chaplains* includes a foreword by Steve Nolan 2020

### Further information



**John Wonnacott**

Specialist Palliative  
Care Chaplain

Macmillan Specialist  
Palliative Care Unit,  
Antrim Area Hospital

**John.Wonnacott@  
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At the heart of spiritual care are compassion and respect; 'a way of seeing and listening to each one in the whole context of their culture and relationships, thereby giving each his or her intrinsic value'<sup>1</sup>. This includes entering their world by letting them set the agenda. As Nouwen says; 'the [person] who can be silent with us in our hour of grief, who can tolerate not knowing, not curing, not healing and face the reality of our powerlessness is the [person] that cares'<sup>2</sup>.

I have had the privilege of working as a chaplain in the Macmillan Specialist Palliative Care (SPC) Unit based in Antrim Hospital for the past three years. I am grateful to the Methodist Church in Ireland, who gave me permission to move from local church ministry to Macmillan chaplaincy.

After leaving parish ministry, I entered a world of competent professionals and capable volunteers, caring for very ill people and supporting their loved ones. Being part of the compassionate and resilient multidisciplinary team has been a challenging but also an inspiring experience. There was a new language to learn and an unfamiliar environment to navigate.

I soon discovered the uniqueness of a palliative care chaplain: to be unconditionally available for everyone, be they someone who is ill, their loved ones or a member of the team, irrespective of age, gender, lifestyle, creed or beliefs. For I believe that everyone is a spiritual being with spiritual needs to be met and a spiritual pulse to be attended to.

When there are unresolved issues around the meaning of life, such as

concerns about hope, unresolved forgiveness or struggles with relationships, these can interfere with the quality of life, the effectiveness of treatment and peace at the end of life. I work as part of the multidisciplinary team, providing expert spiritual knowledge in these complex plans of care.

With trust and openness in place, a safe space is created where sensitive conversations can be encouraged and fostered between the patient, family and myself. Sometimes this involves direct talking, other times it involves more figurative language. For instance, I asked one patient whether the 'elephant' in the room had been named; that is, had he shared his last wishes with his loved ones? He replied, 'We know that it has a trunk, a tail and four legs but we haven't yet called it an elephant'. When I returned a few days later, his first comment was, 'I discussed with my wife about the flowers I want'. After that, the conversation flowed. He died not long afterwards.

**With trust and openness in place, a safe space is created.**

Another person commented that the team 'listened until I could hear myself'. I believe it is more important to know the right questions than the right answers. To be that non-judgmental, confidential, vulnerable, compassionate and empowering presence is an honour.






Support with the same values is offered to the multidisciplinary team through individual conversations, group support, pauses for reflection, debriefs and educational input. This is particularly important where an accumulation of grief and loss can have a significant impact on everyone who delivers palliative care. The team offers person-centered, holistic care, enabling the purpose-built facility (with 12 bedded individual rooms) to be an oasis for all. It opened nine years ago and was the culmination of partnership between Macmillan and the Northern Health and Social Care Trust (NHSCT).

Beyond the ongoing pastoral care in the unit, I lead in several areas. I organise the annual carol service and blessing of hands, as well as organising and sharing in Thanksgiving and wedding services. I provide spiritual support to patients known to the Macmillan Clinical Nurse Specialist in Antrim Hospital. I am a resource for the NHSCT, teaching spirituality and spiritual care, as well as signposting staff to resources within the Trust and beyond. In addition, research is an increasingly important aspect of my work. The Northern Ireland Chaplaincy Research Network's recently published

*Guide to Research* underlined that 'evidence-based care is globally established as the culture of modern health care'<sup>3</sup>.

COVID-19 has brought into sharper focus the spiritual needs for all, be they ill or involved in caring for others. For ourselves, the temporary relocation of the unit to the community, together with the sense of fear and uncertainty regarding the disease, have highlighted our vulnerability. I have found myself encouraging others to express these feelings and to find physical, emotional, social and spiritual support. I provide an important link when either loved ones or a spiritual leader cannot be present. Teaching is now delivered by webinars, making chaplaincy accessible to a much wider audience of healthcare professionals.

Undoubtedly the learning from this pandemic will inform our practice in what feels like a new beginning as, in partnership with the team, I accompany others as they attend to their spiritual needs in the midst of fears, concerns, hopes and dreams. 

---

**Macmillan Unit team, Antrim Area Hospital**  
**L-R Alison Foster, Medical Secretary;**  
**Elaine Moore, HCA;**  
**Nicola Doherty, HCA;**  
**Amanda Mellon, Social Worker;**  
**Lynette Kelly, Team Secretary;**  
**Mary-Ann McCann, Specialist Palliative Care Consultant;**  
**Jayne McAuley, Specialist Palliative Care Consultant,**  
**Petrina Davey, Speciality Doctor;**  
**Celine Neal, HCA;**  
**Kerrie Davidson, Student Nurse;**  
**and Marie McCausland, Staff Nurse.**

## Providing cancer information and support for the deaf community

Maria Leadbeater and Dawn Warrington, Macmillan Information and Support Centre Leads; Sheree Hall, Lead Cancer Nurse; and Niki Johnson, Deaf Macmillan Co-ordinator, on a pilot project to provide accessible information and support to the deaf community.

### Further information



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### Information barriers

Deafness is the third most common disability in the world, but it is largely invisible and often misunderstood by healthcare professionals. From the experiences of deaf people who have used the Macmillan Information and Support Centre at Chesterfield Royal Hospital, we became aware of major obstacles to accessing information and support.

A deaf person's main way of communicating is not always through written information. According to a recent evaluation of the Macmillan Deaf Cancer Support Service, people who are culturally deaf and whose preferred language is British Sign Language (BSL) face significant barriers to accessing NHS services and managing their health conditions. This can lead to poor health outcomes. Many deaf people lack the necessary information to help their recovery, despite seeing many healthcare professionals<sup>1</sup>.

Macmillan recently funded a fixed-term support service for deaf people living with cancer whose first language is BSL. A pilot group was created to give deaf people information on cancer survivorship issues, with BSL interpreters available.

### Planning phase

We adapted our existing 'Moving on after cancer treatment' course and Breast Cancer Now's 'Moving forward after breast cancer treatment' course for deaf people and their families. The aim was to give them an opportunity to get information and ask questions. To allow time for the

presentations and interpretation, we decided to run two full-day sessions (over two weeks).

The topics covered at the sessions included diet and cancer, getting active, managing stress and fears, welfare and benefits. We showed the group a picture of possible physical and emotional effects of cancer to start a discussion, and they asked about several additional issues:

- how to look after dry or oily skin
- general short-term and long-term side effects of cancer treatments
- the difference between chemotherapy and radiotherapy
- dangers of air travel, such as flying with a swollen arm (lymphoedema)
- cannabis oil and other alternative treatments
- effects of the menopause and other physical symptoms of treatment.

All staff involved were given training on the specific needs of deaf people and how to communicate with them.

We carefully considered how to advertise and allocate places on the course as advertising with leaflets and arranging telephone bookings would not have worked. We therefore promoted the sessions through contacts in the deaf community across the Midlands and using the centre's social media.

Interpreter availability was vital and three BSL interpreters were present at both sessions. We sent them presentations in advance to ensure that they were familiar with the medical terminology. We also had to plan car



parking in advance, as exiting the hospital car park involves buzzing to speak to security staff.

When preparing information packs, we checked that the DVDs had subtitles and removed any Macmillan materials promoting a telephone helpline number. We planned to gather feedback by an interpreter asking questions after each session and video recording people's responses (with consent) to be transcribed later.

### Course attendance

20 people initially booked onto the course, with 14 attending the first day and 16 attending the second day.

The time that had passed since the attendees' diagnosis was quite varied. Several people commented that they previously had no accessible health information and, as a result, their understanding was poor. They were keen to learn about cancer and make sense of their own, or their partner's, cancer experience many years after treatment.

### Evaluation

There was a high level of satisfaction with the events. Everyone stated that they would recommend the course to others who have finished treatment.

One attendee commented, 'There are always lots of leaflets giving information, but the jargon often makes it inaccessible for deaf people. Being able to access all this information in my own language (BSL) has given me a much better insight and is much easier for me to understand.'

Others said that the events were great as 'some deaf people are very scared of coming into a centre where everybody is hearing' and that they would recommend them to all deaf people who have cancer: 'It is vital – the deaf community are behind in terms of knowledge and education.'


The evaluation shows that attending the course had a huge impact, which would benefit someone's recovery and return to a healthy lifestyle. It highlights deaf people's relief at having information delivered appropriately for them, and therefore emphasises the need for these sessions across the deaf community.

### Recommendations

We believe the starting point should be that deaf awareness is part of mandatory training for health and social care professionals. This training is very specialist, and Deaf Cancer support, run by Self Help UK, are the only group in the UK who currently offer a tailor-made package providing specific information for medical and healthcare professionals. See [selfhelp.org.uk/Deaf\\_Cancer\\_Support](https://selfhelp.org.uk/Deaf_Cancer_Support)

Cancer information and support should be tailored to avoid giving large amounts of written information, if this is not a person's main way of communicating. Deaf people often struggle with basic English, and their learning style is very visual. We should consider using easy read information booklets and videos for this audience.

Hospital staff should be familiar with how to book BSL interpreters in their area. Short Message Service (SMS) systems to aid communication should also be available in hospital department and wards, where possible.

At Chesterfield, we plan to work with the region's Deaf Cancer Support group to offer cancer survivorship sessions at their future meetings. For centres and hospitals delivering survivorship or health and wellbeing sessions, we would strongly recommend offering similar sessions for the deaf community. 

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### Further information



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## Move More Northern Ireland

The Move More Northern Ireland team explains the project and how it has been affected by the coronavirus (COVID-19) pandemic.

### Scope of the project

Move More Northern Ireland is a physical activity programme made up of 11 individual Move More projects, covering all of Northern Ireland (NI). Each project is a partnership and contract between Macmillan and the relevant council and leisure provider, with a full-time, dedicated Move More coordinator. The first projects began in 2017, and the last one was established in August 2019, when Move More NI became a regional service. Overall statistics show that the programme has received 5,000 referrals to date and engaged with 4,500 participants – this equates to over 70,000 participant engagements.

### Building strong relationships

Move More NI coordinators have established strong relationships across Health and Social Care Trusts, playing an active role within health and wellbeing events and receiving direct referrals from healthcare professionals. They are strong advocates of all Macmillan services, with excellent local knowledge. Moreover, they have relationships with Macmillan professionals, cancer services, Macmillan information and support managers, welfare benefits advisers, volunteer services as well as local navigators and community and voluntary organisations. This provides the opportunity for constant cross-referral to each other's services, which ensures a personalised response to the needs of people living with cancer in Northern Ireland.

Referral onto the programme can be through a health professional, self-referral or a family member or friend. The coordinator is the central point of contact for referrals and will

organise and facilitate the intervention to suit the needs of the individual. Each Move More coordinator develops a close and trusted bond with their participants, offering a vital source of emotional support for individuals as well as collectively through classes.

The projects also provide vital peer support between the participants. Before COVID-19, this was both at cancer specific classes (there were more than 60 classes delivered across NI each week) and through WhatsApp groups and regional events.

Macmillan Partnership Managers identified a number of Trusts across the UK using WhatsApp during the pandemic. But there may be specific rules in some Trusts about using this technology.

### Responding to COVID-19

During the coronavirus pandemic, Move More coordinators have been working from home to sustain the vital service for new and existing participants. While face-to-face classes and appointments are not possible, the coordinators have been working on fun and engaging ways to keep participants motivated and active at home. The Move More NI YouTube channel was launched on 26 March and includes a range of exercise videos.

Move More Coordinator Kelly Irwin, said: 'Like all Move More coordinators, I'm usually based in our local leisure facilities or out and about meeting participants. The YouTube channel has been a great way to sustain activity and link up with our participants during lockdown.'

**The YouTube channel has been a great way to sustain activity and link up with our participants during lockdown.**

**Kelly Irwin**

Move More Coordinator

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### A virtual challenge


With regional events cancelled, coordinators Claire and Catherine developed the 'round the world' virtual challenge. They identified how many steps it would take to climb certain landmarks, and encouraged people to climb as many as they could virtually. This involved people building up their steps every day using a front doorstep, bottom stair or kerb, and keeping track of their daily tally. The coordinators developed a pack to support those getting involved and, encouraged them to take part at an appropriate level for their fitness. Participants shared videos and updates with us on their progress and actively encouraged their peers to take part. One participant, Helen, says that the challenge is literally keeping her on her toes!

'I certainly miss catching up in person, as much for the social benefits as the important exercise, but Kelly and her colleagues are keeping us busy. This challenge is a lot of fun – it's great to have a target to concentrate on and there will no doubt be a bit of good-hearted competition across the groups! Many of us stay in touch through WhatsApp groups, so we're only ever a message away from some encouragement and inspiration.'

### Engaging with technology

Queens University Belfast approached Move More NI about an evaluation of the impact of COVID-19 restrictions on the physical activity of people living with cancer, focusing on how people are engaging with technology. This was timely as our services are being delivered through technology, namely the Move More NI YouTube channel, Zoom, WhatsApp, text and by phone. The evaluation was conducted during June, with over 377 responses. The analysis and reports will help inform Move More NI delivery moving forward, when many people living with cancer are continuing to shield.

### Looking to the future

The coordinators know that Move More NI may need to provide two parallel services in the months ahead. Some people living with cancer may be able to return to a different kind of group class delivery service, incorporating social distancing. But others may need to continue shielding and we will need to keep making use of technology to provide a service for those people. 



**Move More Northern Ireland team**

**Back row L-R:**  
Claire Murphy, Eimear Hagan, Catherine Bell Allen, Laura McGrath, Nuala McVeigh, Kelly Irwin.

**Front Row L-R:**  
Alan McCausland, Aaron Irwin, Aiden McCarron, Conor Fox, Sean Hargan.



# Tackling barriers to financial support for cancer patients with no recourse to public funds

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## Further information



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Hannah McKearnen, Macmillan Information and Support Service Coordinator, on the lack of financial support for people living with cancer who have no recourse to public funds.

### Financial burden

Research funded by Macmillan shows that families dealing with cancer face a 'huge financial burden' in addition to their diagnosis<sup>1</sup>. As well as causing a loss of income because the patient and their carer are less able to work, cancer also comes with increased expenses such as utility bills from spending more time at home, transport costs from travelling to appointments and additional childcare. Benefits such as Employment and Support Allowance and Universal Credit can help, but for those with no recourse to public funds (NRPF) there is little support available.

### Immigration status

Unlike refugees, people with NRPF usually arrive in the UK from non-EU countries on work or marital visas. They can legally live, work and pay national insurance, and their status is categorised as 'limited leave to remain' (LLR)<sup>2</sup>. They might have travelled to the country alone, or with their family. They may have family who are already British citizens. While this group can access NHS treatment free of charge, they have no access to public funds to support themselves financially if they become unwell.

### Case study

One case study is Lucy (not her real name). She is a cancer patient in her 40s, who lived in North Manchester with her teenage son. She came to the UK from Nigeria. Lucy held an LLR visa and had three jobs to pay her bills and support her son. Less than 12 months later, she was diagnosed with breast cancer. She was unable to work while having treatment and because of

her LLR status, she could not access any financial support for herself and her child. This led to her sacrificing her cancer treatment and leaving the country to live with a friend in Italy, hoping the friend could look after them both. Lucy suffered significant psychological trauma as a result of the experience.

We approached local councils and the Home Office to find out the number of people living in the country with NRPF and were told that there is no record of current numbers. We know that Lucy is not an isolated case. At Pennine alone (which covers areas around Manchester including Heywood, Middleton, Rochdale, Oldham, Bury and North Manchester), we have supported four families in the past nine months who were facing financial hardship after a cancer diagnosis as a result of having NRPF.

### Challenging the rules

Recently our centre manager, Charlotte Brosnan, set out to challenge these rules for a family in desperate need of support. Nina (not her real name) is in her 40s and lives in the UK with her husband and four-year-old son, who is disabled. Nina's husband is a UK citizen and her son was born in the UK. She is originally from Pakistan, but was living here on a marital visa and her status was LLR. When Nina was diagnosed with metastatic bowel cancer, the family found themselves facing significant financial hardship. Her husband was working and struggling to care for both her and their disabled son. Nina, who was in and out of hospice care, was unable to claim any benefits.



## There is a clear gap in support for this vulnerable group of people.


Charlotte sought advice from local organisations and solicitors, but they had no information or resources available for the situation that Nina was facing. They all advised that nothing could be done, so Charlotte prepared a case for the Home Office by herself to have Nina's immigration status changed. This included filling in Home Office application forms and gathering information from the family dating back seven years.

The procedure was complex, but Nina's case was eventually successful. The Home Office granted Nina access to public funding under special rules. These special rules can be evoked if a person's human rights are deemed to be compromised. The restrictions on accessing public funds were lifted, meaning that the

family could access vital support to ease the financial burden for the remainder of Nina's life. Charlotte was recognised for her efforts with a 'You are amazing' award from Macmillan.

### Lack of support

There is a clear gap in support for this vulnerable group of people. We have seen that families living in the UK with LLR status often face unimaginable trauma and financial hardship after receiving a cancer diagnosis. We find that there are few resources to support these patients.

Moreover, the procedure to change someone's immigration status and evoke special rules is demanding and complicated for families who are already experiencing significant stress in their lives. Nina's case was viewed by the Home Office as compassion in exceptional circumstances. We know there are many other cases that do not reach the same outcome. 

**Charlotte Brosnan,**  
Macmillan  
Information and  
Support Service  
Manager, being  
presented with  
her 'You are  
Amazing' award  
by Ian Ainscough,  
Macmillan  
Partnership  
Quality Lead.



# Hope, Hints and How To: Helping you respond to living and dying issues during COVID-19

Amanda Mellon, Macmillan Specialist Social Worker and Gillian Thomas, Macmillan Specialist Palliative Care Social Worker, on developing and using an online resource to help people through the coronavirus (COVID-19) pandemic.

## Further information



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## A source of support

As Macmillan specialist social workers in Northern Ireland, we provide valuable psychosocial and practical support to adults with complex palliative care needs and the people close to them. Based in the Northern and Western Health and Social Care Trusts respectively, we work as part of multidisciplinary specialist teams in community settings. Our role has been particularly relevant during the COVID-19 pandemic, supporting members of the public and colleagues.

## Developing a new online resource

At the start of April 2020, we were involved in the production of an online resource, available to everyone, called 'Hope, Hints and How To: Helping you respond to living and dying issues during COVID-19'. The short videos gently offer some ideas and information on topics including:

- Holding on to hope in challenging times
- Advance Care Planning
- Facilitating difficult conversations
- Supporting children to cope with bereavement
- Grieving and support
- Self-care for frontline workers and managers
- Spirituality.

The resource is relevant for anyone, including professionals, community groups and those in the voluntary sector or churches, who are trying to support others during the pandemic.

## Working in partnership

The Northern Ireland Social Care Council (NISCC), which is the social care workforce regulatory body, was proactive in working in partnership with a range of providers to develop this library of accessible information. It brought together the voices of very experienced social work and chaplaincy colleagues from various organisations across Northern Ireland, including Macmillan, Health and Social Care Trusts, hospices and Queens University Belfast. This reflects their leadership and commitment to supporting communities through the most challenging of times.

Available in the public domain, the NISCC resource upholds important social work values and principles such as empowering people and promoting wellbeing.

## A time of crisis

As social workers, we are attuned to noticing and responding to the impact of COVID-19 on our communities.

At a time when people are experiencing a change in their social supports, increased levels of anxiety and uncertainty about the future, access to sound, practical information and advice is vital.

Developing such a resource has been equally humbling and thought-provoking. Being social work professionals does not make us immune from experiencing the impact of COVID-19 in our own personal lives. However, by reflecting on our unique



specialist skills, we have recognised our responsibility to share our knowledge and support our communities.

Social workers are specifically trained to support people, families and communities at times of crisis, regardless of the cause, so this is second nature to us. The pandemic has put living and dying issues into the spotlight and has emphasised their relevance for everybody.

### Evaluation

The NISCC resource was created in a week to ensure timely support was available. It is a privilege to know the resource has been so well received across Ireland and Scotland, as well as in Northern Ireland.


These are some examples of feedback from Health and Social Care Trust colleagues in nursing, pharmacy, chaplaincy, Macmillan Cancer Support NI and Corporate Communications:

- 'I watched all the video clips this morning and found them excellent and extremely helpful.'
- 'AMAZING...Tough watching but an excellent resource.'

- 'This is such a great resource by the NISCC – I will be passing it on to different chaplaincy contacts to make sure that they are up to speed with it. Well done to you and all involved. For such a helpful and accessible resource to be pulled together in that time is stunning.'
- 'Really valuable messages that are relevant for everyone. I'm going to share the resource with all of our professionals.'
- 'This is indeed a lovely resource, very nicely put together and I have no doubt it will be very much required.'

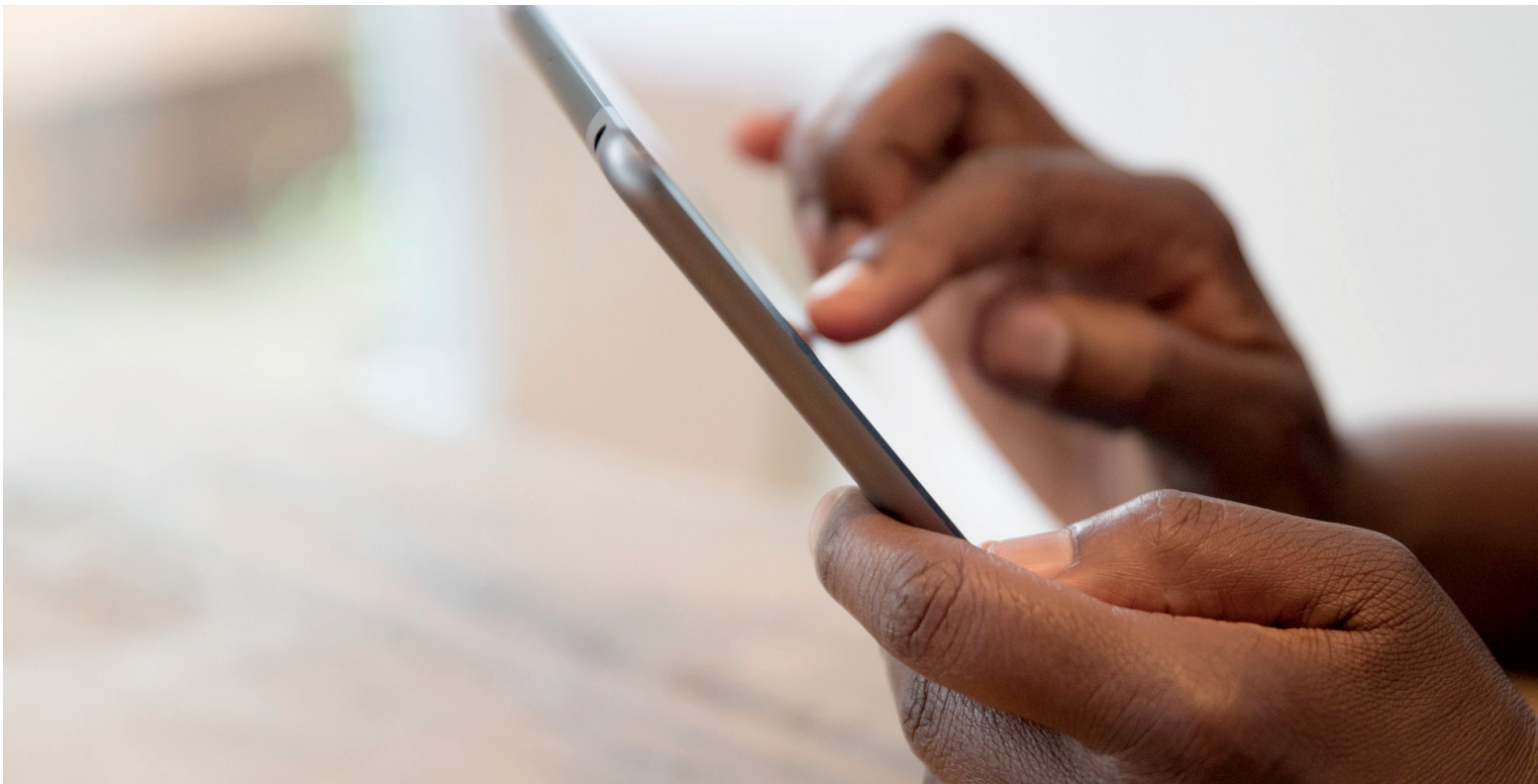
### Holding on to hope

Throughout the pandemic, holding on to hope has been vital in keeping key workers and members of the public going. Hopefully, the lessons that we have learned about living and dying will help us all in the future.

You can access this resource by visiting [learningzone.niscc.info](https://learningzone.niscc.info) and clicking on Learning Resources. 

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The resource provides short videos with ideas and information for anyone trying to support others during the pandemic.



## Supporting cancer patients and staff during the coronavirus pandemic

Elliot Graves, Senior Project Manager; Clare Byrne, Lead Cancer Nurse; and Joanne Kinsey, Cancer Community Support Lead Nurse, on developing a virtual wellbeing service at Liverpool University Hospitals NHS Foundation Trust (LUHFT).

Patients who thought they would be abandoned found they were offered a listening ear and access to knowledge and expertise.

**Clare Byrne**  
Lead Cancer Nurse

### Further information

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### A new model of virtual support

At the outset of the coronavirus (COVID-19) pandemic, a series of unique issues relating to people living with cancer were anticipated:

- changes and delays in diagnosis and treatment
- reduced key-worker capacity to support patients and provide a route back into secondary care
- lack of the usual support networks for cancer patients due to social distancing and shielding.

A virtual wellbeing service was therefore planned to support patients and staff at LUHFT during the COVID-19 pandemic, focusing on psychological and mental health support.

The model recognised the need for both clinical and non-clinical assessment and support. It included a lead clinical nurse specialist (CNS) post and a network approach to use the expertise and resources within small community teams. These teams, already established across the four North Mersey Clinical Commissioning Groups (CCGs), have a routine role in Holistic Needs Assessments (HNA) and knowledge of local community-based NHS, council and voluntary services. This made them well placed to deliver community-based virtual patient assessment and support during the pandemic.

The model was developed and agreed in collaboration with key partners across North Mersey. Macmillan partnership funding was obtained,

which secured the lead CNS post for 12 months and funds for a partnership with the Citizens Advice Bureau and Sunflowers cancer charity.

A clinical supervision model was developed in partnership with LUHFT psychology colleagues, to offer virtual clinical group supervision sessions and 1:1s every week. Community staff involved in delivering the service also received communication skills training to equip them for challenging conversations, led by LUHFT psychology colleagues.

Within two weeks, the first patients were referred to the service.

### How the service works

Colleagues across the cancer pathway identify patients in need of support during the COVID-19 pandemic, such as those who are newly diagnosed, vulnerable or require changes to their treatment.

On the next working day, the Macmillan lead CNS conducts an initial assessment call with the patient. Where appropriate, patients are then referred onto their relevant community navigator or HNA team (two-thirds of patients are referred).

Community teams offer urgent (same day) or routine (within three days) call backs. Patients' needs are then comprehensively assessed, and they are signposted or referred to virtual local support covering mental health, emotional, practical or financial issues.

Support from community teams is agreed with patients, underpinned by a clear route to escalate queries or concerns through the lead nurse. A community navigator at the Liverpool Wellbeing Enterprise said, 'The lead nurse can answer any clinical questions about patients. This has been invaluable as the CNSs have been incredibly busy during COVID-19.'

A navigator in Sefton said, 'A gentleman with a bowel cancer had his operation cancelled due to COVID-19. His condition deteriorated, and he was in a great deal of pain. By liaising with the central point of contact for the navigators and his CNS, we managed to get his operation brought forward.'

### **An evolving service**

Clare Byrne, Lead Cancer Nurse at Aintree Hospital, commented, 'The service has quickly evolved to proactively support patients and those close to them. Patients who thought they would be abandoned, against a backdrop of limited treatment options, found they were offered a listening ear and access to knowledge and expertise, helping them maintain hope.'


Not only has the service supported patients living with uncertainty, it has also minimised the stress levels of CNSs. As cancer diagnostics resume, the service is also supporting patients diagnosed with advanced disease in the transition to palliative treatment.'

### **Success to date**

During the first seven weeks, the service supported 109 people living with cancer. To address these patients' complex needs, joint working and communication were required between the Macmillan lead CNS, hospital teams and community navigators. The service has rapidly built relationships and encouraged collaboration across specialities and organisations, spanning primary, secondary and community and voluntary care.



In the context of COVID-19, the new model has empowered community navigator and key worker teams to go above and beyond their roles. They have demonstrated their incredible skills, empathy and resilience in supporting patients through challenging times. The essential role of these staff in holistic support and care co-ordination will no doubt underpin future service design.

Funding for the Macmillan lead CNS has been secured for another 12 months through Macmillan, as well as for two more Citizens Advice Bureau link workers. These funding commitments, and Macmillan's partnership in this work, recognise that the approach offers principles beyond the immediate crisis and recovery of the COVID-19 pandemic. The virtual wellbeing support model may become part of the 'new normal' for cancer services. 

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**Patients have an initial call from a Macmillan lead CNS and are referred onto their community navigator or HNA team.**

### **Further information**



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## Attend Anywhere: Using video calling for counselling and hypnotherapy sessions

Julie Pieczarka, Macmillan Information and Support Manager, on the new video consulting service Attend Anywhere at Leighton Hospital in Crewe.

### Further information



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### Developing Attend Anywhere

The Macmillan Information and Support Service, based in the Macmillan Unit of Leighton Hospital in Crewe, has set up a new video consulting service. This allows cancer patients to receive counselling and hypnotherapy throughout the coronavirus (COVID-19) pandemic.

Normally, patients and carers can access an information drop-in service in the unit, Help to Overcome Problems Effectively (HOPE) recovery courses and Look Good Feel Better events. However, these face-to-face services were suspended when lockdown restrictions were put in place.

We immediately recognised the need to support patients in different ways and started working on projects to allow us to continue offering information and supportive care.

Patients and carers were initially worried about how COVID-19 would affect them, and how they would get help from local services. For this reason, our information service has been available throughout the pandemic by telephone directing patients to clinical teams, and local and national advice and support.

In April, Clare Bloor, Macmillan Information Co-ordinator, and I started working with the counselling and hypnotherapy team to shape a new service. Our aim was to offer the best personal and face-to-face feel we could, to support patients and carers with the emotional impact of cancer.

### Running the virtual service

Attend Anywhere is a free video consulting software, allowing a secure and confidential conversation between patients, counsellors and a hypnotherapist. Users need to use Google Chrome or Safari as their web browser to use the software. It uses a secure URL to put patients into a virtual waiting room, before connecting them directly. This has allowed five volunteer counsellors and a hypnotherapist to continue providing support for their patients.

Clare and I manage and run the service, and have worked to produce robust governance and procedures for the project. We also cascaded training throughout the team before the official launch on 5 May. We have worked closely with the counsellors and hypnotherapist through conference calls to troubleshoot and devise administrative systems to support the new way of working.

At first, existing patients were invited to access this new support offer. We then started taking new referrals from the unit's specialist nurses and Macmillan professionals.

By the end of June, counselling and hypnotherapy support was back to full capacity and Attend Anywhere was in place for patients wishing to access the new virtual, face-to-face contact. Patients who did not have access to a computer, laptop, tablet or smartphone could get support through a telephone service.

We have been really motivated in getting video consulting off the ground. We were one of the first services in the hospital to use the system and we have now heard that Attend Anywhere is being used across the Trust, which is great to see.

Clare and I have also been on hand to assist patients who do not feel confident with video consulting. We wanted to do whatever we could to make people more comfortable, such as offering a trial run to reduce anxiety, so they can concentrate on their support in the consultation itself.

#### Feedback from counsellors

Feedback from counsellors has been positive, including that video consulting:

- gives patients time to think before they speak because they can be 'seen' finding their words and thoughts
- allows for a more personal conversation with patients because they can see the person they are talking to, and the counsellor can react to visual cues
- has been easy to use, and even if there are internet connection issues, they can simply switch to the phone.

One counsellor said, 'Cancer patients in treatment are still shielding and they want to be where they feel safe, in their own homes. Patients have said "I am so fearful of getting this virus; I would not want face-to-face therapy, I would have just had to deal with the anxieties on my own".'

Another said, 'One of my clients told me she would have felt too fatigued to attend a physical counselling appointment after her chemotherapy, but felt she had enough energy to have a session via Attend Anywhere as she didn't have to travel, do her hair and she could wear pyjamas.'

Feedback from the hypnotherapist included that patients wearing headphones on the video call enhanced the benefits of the therapy.

#### Feedback from patients


Patients have reported that there are no travel arrangements, worries about parking or fear of contracting an illness at hospital. Plus, appointments are either on time or early. These issues are incredibly important to patients who are in a high-risk category.

One patient said, 'I'm so grateful to be able to receive hypnotherapy remotely during these difficult times. The online system is easy to use and not having to find safe transport or leave home for these sessions has helped with my anxiety. I hope this service will continue.'

Another patient commented, 'I'm very impressed with the online therapy, it saves travel time and avoids contact (as I'm in a vulnerable group). It's easy to use with minimal setup and is really helpful for my mental wellbeing.'

#### The future of the service

We are continuing to develop and promote the virtual services, and expect to make them a permanent addition to our support offering.

Kate Skinner, Lead Cancer Nurse at Mid Cheshire Hospitals NHS Foundation Trust, said, 'It is great to be able to continue to offer such vital support to patients during a time of great anxiety and uncertainty. I am immensely proud of Julie and Clare in recognising the need to be dynamic, and quickly implement this new model of support.' 

**It is great to be able to continue to offer such vital support to patients during a time of great anxiety and uncertainty.**

**Kate Skinner**  
Lead Cancer Nurse

## Developing information in a rapidly changing environment

Sue Green, Senior Information Development Nurse at Macmillan Cancer Support, on producing information in response to the ever-changing context of the coronavirus (COVID-19) pandemic.

### A time of uncertainty

In March 2020, coronavirus cases were rising daily. For people with cancer, an already difficult and frightening situation was made worse by the threat of this new illness, about which little was known. Were they more at risk? Would it affect their treatment? What might it mean for their prognosis? How could they avoid catching this potentially life-threatening virus?

At this time, the Macmillan Support Line was receiving a high volume of calls about coronavirus and cancer. As a trusted provider of high-quality cancer information, we knew people would be looking to us for answers. It was clear we needed information online as soon as possible.

### An ever-changing situation

We have a robust, quality-assured process that takes time. Our usual review cycle gives us several months to revise and update a topic area. The content then stays online for two to three years. But the ever-changing COVID-19 situation led to a very different way of doing things.

We needed to write, approve and publish content in a matter of days to help people affected by cancer understand how the virus might impact them and what, if anything, they needed to do. We recognised that this information would need updating frequently, possibly daily. As with so much to do with coronavirus, how we put the information together evolved as we learned more about what our users needed. It was also influenced directly by government and NHS guidance.

### Developing our information

At the beginning of March, we started with a brief page about coronavirus and cancer. At this point there was no specific cancer-related guidance, but we needed to provide something. While the initial information was very general, we could acknowledge people's questions and signpost to emotional support. This was important when so many people were experiencing fear and uncertainty. By the end of March, we had a coronavirus information hub online with various pages covering coronavirus and cancer generally, coronavirus and cancer treatments, end of life issues, Macmillan's services and finances and work. We also developed specific pages about shielding, self-isolation and social distancing. All these terms were becoming everyday phrases, but they were confusing and government guidance was complex and detailed. People living with or after cancer needed to know what was relevant for them.

Another challenge was quality assurance and approving content for publication. We needed approval from our medical experts quickly. We worked closely with colleagues in Macmillan who have expertise in specific areas. We were also in frequent contact with our chief medical officer (a GP) and chief medical editor (a consultant oncologist). They were key in signing off content quickly, so we could publish it as soon as possible. Our digital team were also integral in developing the information and getting it online. Throughout March and April, they prioritised coronavirus content over everything else.

### Further information



**Sue Green**

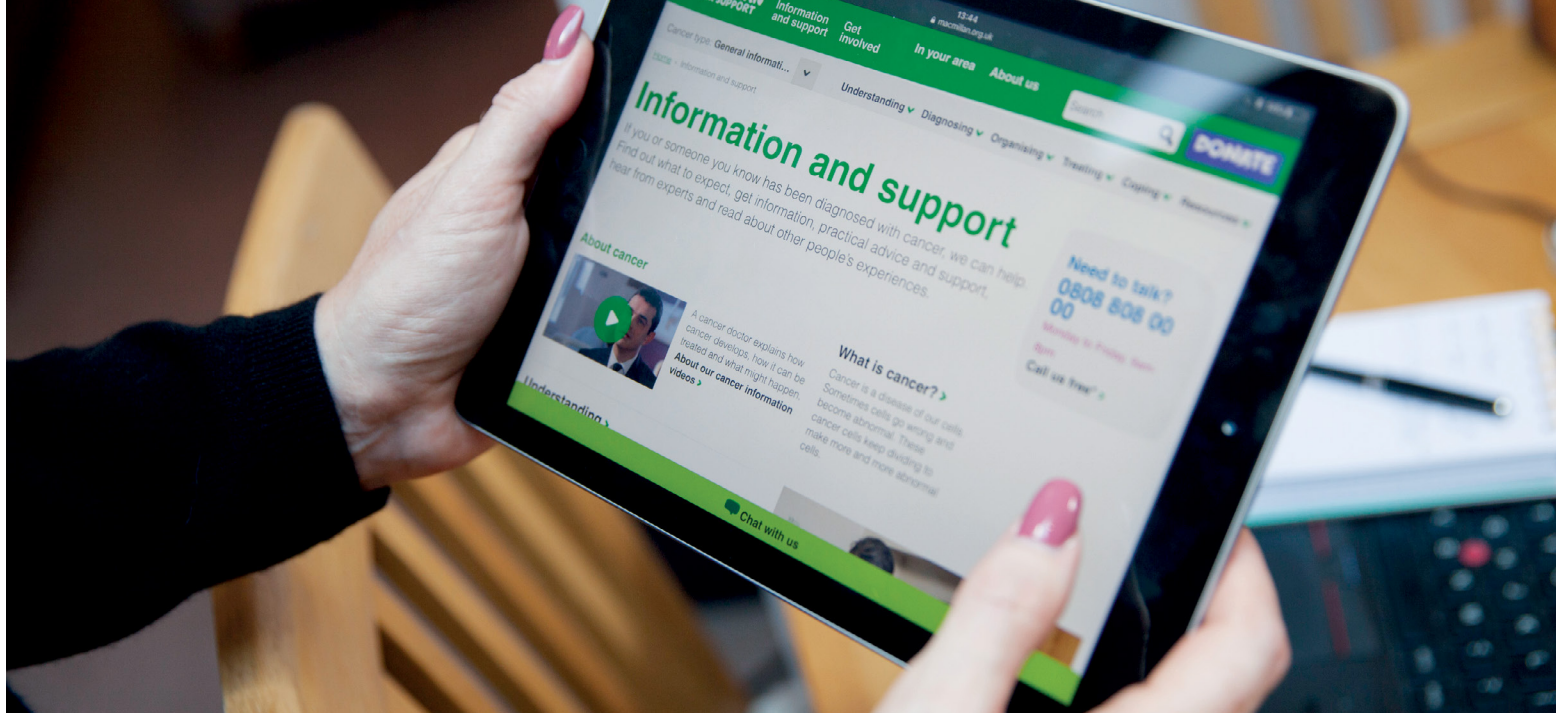
Senior Information  
Development Nurse

Macmillan Cancer Support

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[macmillan.org.uk/macvoice](https://macmillan.org.uk/macvoice)





**As with so much to do with coronavirus, how we put the information together evolved as we learned more about what was needed by our users.**

**Sue Green**  
Senior Information  
Development Nurse

They contributed their expertise and skills to ensure it ranked high in search engines and was optimised to meet the needs of our users.

#### **Expanding our information**

Over time, we introduced information on coronavirus for health professionals. We also recognised that we needed to provide or signpost to information in accessible formats, such as easy read or other languages. In addition, guidance in the four nations of the UK has become more varied and we needed to reflect that in our information.

#### **Teamwork at its best**

On reflection, I realise how little source information we had at that time on which to base our content. And what a challenge it was to respond to needs in such a fast-changing environment. Going forward, we can take the learnings from this experience as we look at our processes for developing and updating information.

At an extraordinary time, we have demonstrated an example of teamwork at its best across Macmillan. We have all worked together and used our expertise and skills to provide coronavirus information that is as accurate, timely, searchable and accessible as possible. Visit [macmillan.org.uk/coronavirus](https://macmillan.org.uk/coronavirus) 

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**We have worked to provide coronavirus information that is as accurate, timely, searchable and accessible as possible.**

## Updated



### Holistic Needs Assessment: Planning your care and support MAC12957\_E05 (Edition 5)

This leaflet is about a Holistic Needs Assessment (HNA). It explains what happens at an HNA and has information about making a care plan.



### Life after cancer treatment MAC11661\_E09 (Edition 9)

This booklet is about coping after cancer treatment finishes, including managing side effects, follow-up care, and making healthy lifestyle changes.



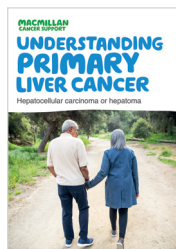
### Understanding anal cancer MAC14811\_E03 (Edition 3)

This booklet is about anal cancer. It explains the signs and symptoms of anal cancer, as well as how it is diagnosed and how it may be treated.



### Understanding colon cancer MAC12474\_E05 (Edition 5)

This booklet is about colon cancer. It explains the signs and symptoms of colon cancer, as well as how it is diagnosed and how it may be treated.



### Understanding primary liver cancer MAC11917\_E05 (Edition 5)

This booklet is about the most common type of primary liver cancer, hepatocellular carcinoma (HCC). It explains the signs and symptoms of primary liver cancer as well as how it is diagnosed and how it may be treated.



### Understanding rectal cancer MAC12475\_E05 (Edition 5)

This booklet is about rectal cancer. It explains the signs and symptoms of rectal cancer, as well as how it is diagnosed and how it may be treated.

You can order our booklets and leaflets at [be.macmillan.org.uk](https://be.macmillan.org.uk)  
We also have a range of audiobooks at [soundcloud.com/macmillancancer](https://soundcloud.com/macmillancancer)

To find out more about our full range of information, including translations and easy read, visit [macmillan.org.uk](https://macmillan.org.uk)

## Your Dashboard

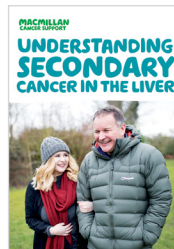
We have launched Your Dashboard, which allows people to create an account on our website to get personalised cancer information and support. By logging in, people living with cancer can get information that's tailored for them. Read more at [macmillan.org.uk/why-join](https://macmillan.org.uk/why-join)

## Macmillan Online Community

We have improved the Online Community to make it easier for people to access support, including linking accounts up with My Dashboard and making it more user-friendly. Visit [macmillan.org.uk/community](https://macmillan.org.uk/community)

## Coronavirus resources on LearnZone

We have a range of information, resources and e-learning to support professionals during the coronavirus (COVID-19) pandemic. Visit [learnzone.org.uk/coronavirus](https://learnzone.org.uk/coronavirus)



### Understanding secondary cancer in the liver MAC11630\_E09 (Edition 9)

This booklet is about secondary cancer in the liver. It explains the signs and symptoms of secondary cancer in the liver as well as how it is diagnosed and how it may be treated.



### What to do after cancer treatment ends: 10 top tips MAC13615\_E04 (Edition 4)

This leaflet is about what to expect and where to get further support after cancer treatment ends.