

Diagnosis, treatment and aftercare from 1970–2016



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People are now twice as likely to survive at least 10 years after being diagnosed with cancer than they were at the start of the 1970sⁱ. In the past 40 years or so better screening and advances in treatment mean we have seen a huge change in what a cancer diagnosis means; it is now a moment that is frequently not lifeending, but nearly always life-changing. That's why Macmillan Cancer Support continues to offer support when people need it most.

The combination of an ageing and growing population and more effective cancer treatment means that we now have unprecedented numbers of people living in the long term after a cancer diagnosis - this will only increase as the years go by. Cancer: Then and now highlights for the first time the extraordinary number of people alive many years after they were diagnosed with cancer. New analysis from Macmillan Cancer Support and Public Health England's National Cancer Registration and Analysis Service (NCRAS) estimates that at least 170,000 people are living with cancer who were diagnosed in the 1970s and 1980s".

This group of long-term survivors will continue to grow in the coming years, with the 2.5 million people currently living with cancer due to increase to at least 4 million by 2030ⁱⁱⁱ. Furthermore, an ageing population means that people's needs are growing ever more complex. Macmillan research shows that there are currently 1.8 million people living with cancer and at least one other long-term health condition, such as heart disease or chronic kidney disease^{iv}.

One constant throughout the decades of progress is that the end of treatment is almost never the full story of someone's cancer experience. Cancer leaves a lifelong legacy for hundreds of thousands of people in the UK. While many people go on to live full lives and are able to put their experience behind them, many others struggle with the physical, emotional and financial effects of a cancer diagnosis and treatment for years after.

Macmillan's role in cancer care has responded to this disease's everchanging challenge. While our central mission of supporting people affected by cancer remains the same, this now involves a lot more than it did 40 years ago. We have evolved from an organisation whose services chiefly supported people at the end of life with a nurse to one that offers a wealth of different services, including many that are non-medical, that support people from the point of diagnosis onwards. Likewise, we have expanded our professional workforce from cancer specialist nurses to include dieticians, financial advisors, physiotherapists and GPs, to name a few.

If we are to understand the challenge cancer poses in the future, it is important to reflect on the recent past. This report looks at how much the cancer story has changed over the years, celebrating progress, but also highlighting persistent problems that would resonate with people living with cancer as much today as 40 years ago. Above all, the cancer care our health service provides must be able to meet the increasingly complex demands that we know will be placed on it in the coming years. This means a more personalised approach to care that really supports people every step of the way through their cancer experience so that they are able to live as full a life as possible.

Lynda Thomas,Chief Executive, Macmillan Cancer Support



Forty years ago a cancer diagnosis was considered not only taboo, but was immediately associated with dying. 'No one talked about cancer,' recalls Sally Jorden, a nurse who started work in the 1960s, and who later became a Macmillan nurse. 'If a patient was diagnosed, their relatives begged us not to tell them. Of course, we had to tell the patient the truth but we understood their loved ones were trying to shield them from what was considered a death sentence.'

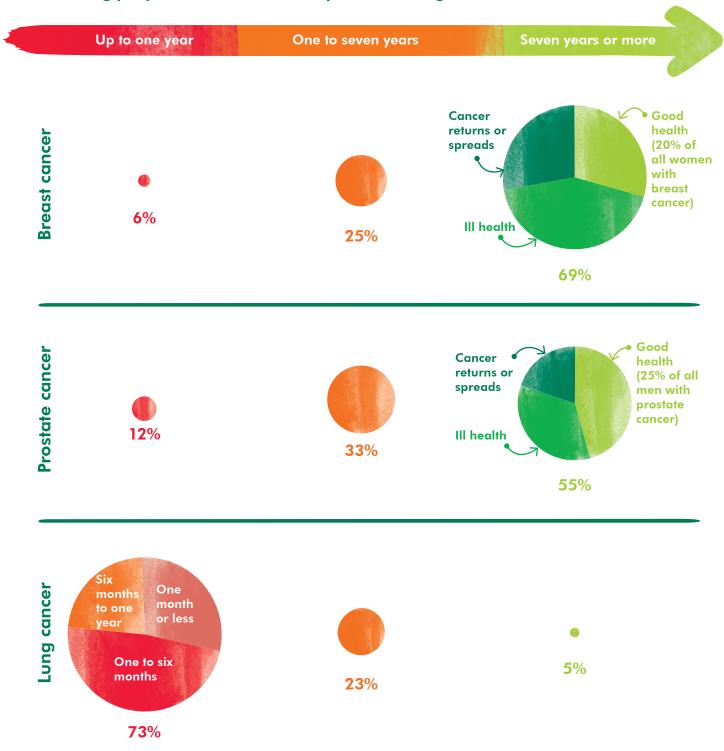
A most basic rule of treating cancer today is the earlier it is detected, the greater someone's chances of survival. Once cancer is suspected, nobody should have to wait any longer than is necessary to get a diagnosis and to start treatment. In this respect the NHS has changed considerably in the 1970s and 1980s there was no fast track once someone was suspected of having cancer, and many people waited for several months from a referral to the start of treatment. Now, if a GP gives their patient an urgent referral and cancer is found, most should expect to start treatment within 62 days.

The rolling out of screening programmes as well as scientific and technological advances in areas such as genetics and medical imaging means that cancer is more likely to be diagnosed at a much earlier stage than in the 1970s and 1980s. MRI, CT and PET scans were first introduced during these decades, meaning cancer could be identified earlier.

Meanwhile, screening for breast cancer was introduced by the NHS in 1988, with all women over the age of 50 being offered automatic access to a mammogram. Screening programmes for cervical, and more recently colorectal cancers have also helped improve earlier diagnosis of these cancers and can also help prevent the disease in the first place.

Survival has improved greatly in recent years, with people now twice as likely to survive at least 10 years after being diagnosed with cancer than they were at the start of the 1970sⁱ. Despite all these advances, survival rates among some cancers such as those of the lung and pancreas remains very low and have hardly changed over the past 30 or 40 years, as the cancer is often caught too late or there is still a lack of effective treatment. And too many people are still only diagnosed after an emergency hospital visit.

How long people with cancer currently live after diagnosisvi



^{*} Proportions may not add up to 100% due to rounding.

Ill health = having at least one of a range of serious health conditions



'One thing that has never changed over the years is how someone reacts when you tell them they have cancer. People still instantly ask themselves, 'am I going to die?' People have much more information when they are diagnosed nowadays, but they are often in 'life and death' mode which means many do not actually take in the information. It is so important for people to have a specialist nurse there to explain what happens next after this life-changing moment.'

Professor Jane Maher
Joint Chief Medical Officer
Macmillan Cancer Support





In the 1970s, the initial nurse posts that Macmillan funded were almost exclusively geared towards palliative care, as comparatively few people survived their disease.

Macmillan is now an innovator in the area of early diagnosis, developing an electronic cancer decision support tool (CDST) to help GPs think of cancer and support them in important decisions about whether someone should be referred to a specialist for further investigation. The CDST calculates the risk that somebody may have cancer, based on a variety of symptoms and factors including age, lifestyle and previous history recorded within the patient notes.

Macmillan is also working with Cancer Research UK to support another initiative to improve early diagnosis. Led by NHS England, the ACE (Accelerate Coordinate, Evaluate) programme has been developed to support and test innovations to speed up the whole process by which people are diagnosed in the NHS.

By identifying and tackling blocks in the system which delay diagnosis, the ACE programme aims to reduce the number of people who are diagnosed after being admitted as an emergency while also improving patient experience, so people are not left to wait anxiously for news.

Macmillan nurses now support over half a million people with cancer every year right from the moment they are given a cancer diagnosis. Macmillan nurses help to explain the nature of someone's cancer and support the next steps in treatment. They are a wealth of expert advice and emotional support to people going through what can be the toughest experience of their life. Macmillan's website and support line are both crucial sources of information for people who have just been diagnosed, as well as those in treatment and beyond.



'In the 1980s there was no one to help or advise. I felt very alone and frightened, and thought I was going to die. I was also very angry with my doctor who had ignored my symptoms and pleas to be referred for two years even though there was a family history of cancer.'

Philippa, 67, from London, diagnosed with colon cancer in 1986

Oncology nurse in the 1980s

'Cancer was hush, hush. Our job was to explain what cancer was in the kindliest way as there were no story lines in television soaps, no magazine features about people with cancer to relate to.'



Every type of cancer treatment has improved over time and cancer is now targeted with far greater precision than in the past. More refined techniques in surgery, radiotherapy and chemotherapy mean that people live with fewer of the particularly significant side effects that people experienced in the 1970s and 80s. But we now see different side effects emerge from newer treatments.

Being treated for cancer continues to be an experience that has a profound impact on a person's life, one that can still leave them with devastating, lifelong consequences. People may have to contend with the loss of part of their body, such as a mastectomy, or side effects from newer forms of chemotherapy. At least 625,000 people in the UK are estimated to be facing poor health or disability after treatment for cancer – approximately one in four (25%) of those living with cancer^{vii}.

In addition to those for whom treatment is very likely to result in a cure, there is now a growing group whose cancer is incurable but treatable in some cases. These people can live for years with their cancer being controlled by a range of treatments such as hormones, chemotherapy, radiotherapy and biological treatments in a way that would not have been possible 40 years ago. It is extremely important that people living with their cancer in this way are supported to have the best possible quality of life.

'While side effects of treatment are often less significant than they were 30 or 40 years ago, the number of people affected by long-term consequences remains significant. We now see fewer of the big side effects such as increased risk of heart attack and stroke we saw after treatment in the 1970s and 80s, but some of the effects doctors consider 'small', such as fatigue and poor bowel control, can have a profound impact on someone's quality of life. Sadly, there is no cancer treatment available at the moment that does not carry a risk of side effects.'

Professor Jane Maher Joint Chief Medical Officer, Macmillan Cancer Support Surgery, still one of the most effective ways to treat cancer, has become much more sophisticated in the past 40 years. The removal of prostate cancer, for example, is now more commonly done by keyhole surgery, which is far less traumatic for the body than open surgery. Before the mid-1980s, breast cancer was usually treated with a mastectomy, but now a lumpectomy can be an option for many people with early-stage breast cancer, which means much more of the breast is conserved, and can lessen problems with body image afterwards. Similarly, since less surgery is now done on the armpit, fewer people suffer from chronic swelling, or lymphoedema, which is a result of lymph nodes being taken out.

Access to surgery does remain a problem for some cancers. For example less surgery is carried out in the UK than in other European countries, and the proportion of people who receive surgery varies widely across the UK^{viii}.

A further inequality is that older people are also less likely to receive surgery than younger people^{ix}.

New surgical techniques continue to emerge, such as the use of robotics, and the experimental 'NanoKnife' technology, which can make surgery possible on tumours that would previously have been considered inoperable.

Radiotherapy was far more crude in the 1970s and 1980s than it is today, and now-obsolete radiotherapy machines and techniques have left many people suffering devastating burns and side effects such as fatigue for years after treatment. Older radiotherapy equipment is gradually being replaced by intensity modulated radiation therapy (IMRT) machines, which focus the radiation more accurately on the cancer, leaving more healthy tissue unaffected – although progress is still too slow in this area. Brachytherapy, or internal radiotherapy, has also increased in use in the NHS since the turn of the 20th century, proving to be an effective treatment for diseases such as prostate, womb and cervical cancer.

Chemotherapy has led to great advances in treating certain cancers. For example, the introduction of chemotherapy drug cisplatin transformed testicular cancer survival rates from the 1970s onwards. Ten-year survival rates for testicular cancer are now predicted to be 98 per cent*.

Chemotherapy was synonymous in the 1970s and 80s with severe side effects such as nausea.

Describing chemotherapy in the 1980s, one Macmillan nurse said: 'Chemotherapy was very experimental and no one knew about the side effects so we couldn't assure patients and say 'it'll be fine'. Some people were put through very harsh chemo when all they wanted was to die in peace.

They knew they were going to die anyway, so didn't understand why they had to go through this.'

There are now many more chemotherapy drugs in use today, with a wide variety of side effects. Today, some of the more well-known side effects can be combated through the widespread use of anti-sickness drugs.

Biological therapies, including immunotherapy, which employs the body's own immune system to attack cancer cells, did not exist at all as a treatment until 10 years ago, and is still an experimental form of treatment. It has been shown to be effective in treating diseases such as malignant melanoma and kidney cancer.

As with other forms of cancer treatment, immunotherapy can produce a range of side effects such as fatigue and nausea.

Other new treatments, such as highintensity focused ultrasound, are currently being trialled. Possible uses of ultrasound include treating cancer that has spread around the body to places such as the bone, as well as prostate and pancreatic cancer.



Advances in treatment in the 1980s meant more cancers became curable, which in turn meant Macmillan's own services broadened beyond the investment in end of life care and cancer care environments that defined much of Macmillan's work in the previous decade.

In 1980 Macmillan launched an educational programme for training doctors, nurses and students in cancer care, and invested £2.5m in expanding Macmillan nursing care teams across the UK. This involved training clinical nurse specialists who for the first time would support people throughout their treatment, advising them on how to mitigate side effects of treatment, as well as the practical aspects.

Macmillan's services expanded rapidly throughout the 1980s, with the first Macmillan GP being appointed in 1986, and the 500th Macmillan nurse being appointed in 1988.

Information for cancer patients about their cancer and their treatment was less developed in the 1970s and 80s. 'May I send my most sincere and grateful thanks and that of Miss... for your generous grant towards her bedding and clothing. When I gave her the money, she was so overcome that her tears were her most eloquent expression of thanks. It might interest you to know that she also said, that knowing that help is available, gives her reason to keep on living.'

Letter to Macmillan from a medical social worker featured in 1971's annual report.

To meet the increasing demand for reliable information the first Macmillan Cancer Information Centre was set up at the Lynda Jackson Centre at Mount Vernon Cancer Care Centre in 1992. There are now currently over 200 Macmillan cancer information services in operation throughout the UK. Today Macmillan also runs mobile information services, which in 2015 helped reach almost 75,000 people on high streets and in town squares across England, Scotland and Wales^{xi}.

It is not only the treatment itself that a person has to cope with – cancer reaches far into people's lives, affecting family, work and finances. Macmillan recognised the financial impact of cancer very early on, and has given grants for more than 90 years, helping individuals and families in need.

Grants can, for example, help people buy new clothes when they lose weight during treatment, or help pay a heating bill when they are out of work and feeling the cold after a chemotherapy session.

Beyond grants, Macmillan now plays a key role in helping people with cancer access much-needed benefits to support them financially while going through treatment. In 2003 Macmillan published a report called *Unclaimed Millions* which estimated that £126.5m was being lost by cancer patients in unclaimed benefits each year^{xii}.

In response to this need the first Macmillan-trained benefit advisers were appointed in 2005. Ten years later, Macmillan secured £280.9m worth of welfare benefits, financial gains and Macmillan grants for people living with cancerxiii. Macmillan has also in recent years campaigned to ensure that people with cancer are not adversely affected by proposed changes to important benefits that help people stay afloat financially when they are ill.

The Macmillan Support Line plays an invaluable role in advising and informing people with cancer and their families through treatment. The service was started in 1997 and today answers 144,000 calls a year across the UK^{xiv}, providing a range of practical, financial and emotional support. This can include help with complex issues such as welfare claims and help with fuel bills, through to some people who simply need a chat at a tough moment during or after treatment.

Macmillan's **online community** has proven to be a vital forum where people with cancer can share their experiences and get support from people who are going through the same thing. In 2015 more than 780,000 people have visited the online community**, which now has more than 100,000 members.



The notion that a person would require help and support to get their life back on track after cancer treatment finished wasn't commonplace in the 1970s and for much of the 80s; little emphasis was given to the quality of life someone led if they survived cancer in the long term.

Irrespective of what treatment you had, or how a person was faring after treatment, standard follow up appointments over five years were the norm^{xvi}. But by the end of the 1980s when more people were surviving cancer than ever before, the situation began to change.

Creating partnerships in cancer care

'During the past 15 years advances in treatment and the introduction of new and more effective drugs for pain and symptom control have opened up new possibilities for people with cancer to continue living full and active lives'.

Macmillan's 1988 annual report

Ann Nash, an early Macmillan nurse who worked in cancer care from the mid-70s onwards, explains further in the charity's 1988 annual report:

'From being a taboo subject people are now more willing to talk about cancer and there is much more optimism about life after a cancer diagnosis.'

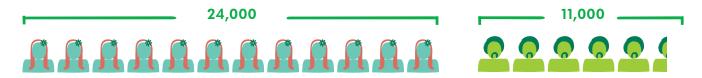
New figures from Macmillan Cancer Support and Public Health England's National Cancer Registration and Analysis Service show that at least 170,000 people are living with cancer who were diagnosed in the 1970s and 1980s^{xvii}. But even today, surviving does not mean that people necessarily live well, and many will have contended with life-long consequences of treatment such as lymphoedema, fatigue and side effects from chemotherapy.



There are around 35,000 people still alive in the UK who were first diagnosed with cancer in the **1970s**ⁱⁱ

Gender

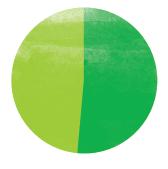
An estimated 24,000 are women and over 11,000 are men



Key = 2,000 people

Age at diagnosis

Around 17,000 people were diagnosed between the age of 40 and 69



More than 18,000 people were diagnosed under the age of 40

Cancer type

Around 8,000 womenwere diagnosed with breast cancer



Around 2,500 people were diagnosed with colorectal cancer

Over 800 people were diagnosed with lung cancer



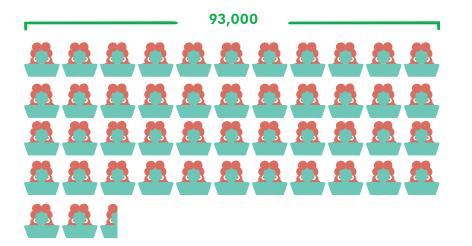
Around 160 men were diagnosed with prostate cancer

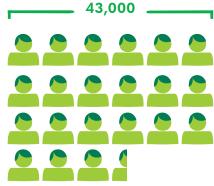


There are around 136,000 people still alive in the UK who were first diagnosed with cancer in the 1980sⁱⁱ

Gender

An estimated 93,000 are women and over 43,000 are men

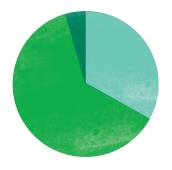




Age at diagnosis

Around 4,600 people were diagnosed aged 70 or over

Around 85,000 people were diagnosed between the age of 40 and 69



Over 45,000 people were diagnosed under the age of 40

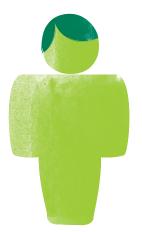
Cancer type

Around
35,000 women
were diagnosed
with breast
cancer



Around 12,000 people were diagnosed with colorectal cancer

Around 3,000 people were diagnosed with lung cancer



Around 1,500 men were diagnosed with prostate cancer

There are now 2.5 million people living with cancer in the UK, and by 2030 at least 4 million people will be living with cancer***iii. Improving survival rates, a growing population and increased life expectancy means more people will live in the long term after diagnosis. This also means more people will live with the long term consequences of treatment. Too often people who finish treatment describe how they feel like they 'fall off a cliff' after treatment, as they are suddenly left alone to contend with the emotional and physical impact of cancer.

To meet this need, and to ensure that people don't feel abandoned after treatment, Macmillan advocates a personalised approach to treatment and aftercare, which looks at a person's full range of needs, be they physical, emotional, practical, financial or social. In partnership with Department of Health and the NHS, Macmillan developed a 'recovery package' to help health and care professionals and people with cancer to identify individual needs and improve the way that care is provided. A major part of this is ensuring that care continues once a person finishes treatment, by making sure they and their GP know what treatment has been given and any consequences of treatment to look out for. The recovery package is due to be rolled out across England as recommended in the 2015 cancer strategy, and is now a major focus of Macmillan's work in Scotland, Wales and Northern Ireland

Over the last decade, Macmillan has worked closely with the NHS to innovate and improve services for people during and after cancer treatment.

A growing body of evidence now shows that physical activity helps not only to manage the often devastating consequences of treatment such as fatigue, depression and heart damage, but also to reduce the risk of the disease worsening, recurring or causing death in people living with cancer. As a result physical activity is recommended as part of the recovery package, and Macmillan has developed a Move More guide for people with cancer to become more active during and after treatmentxix.

Much still needs to be done, however, to dispel the myth that 'rest is best' that was the common advice to people living with cancer in the 1970s and 80s. Recent Macmillan research shows family and friends are still more likely to tell someone with cancer to take it easy than encourage them to do more physical activity^{xx}.

From redesigning follow up pathways to supporting local support groups and raising awareness of the ongoing issues people may face after cancer, Macmillan has led the way in shifting the understanding of cancer.



'It used to be the case that people working in primary care such as GPs were predominantly involved with people who were dying of cancer at home. The increasing number of people surviving cancer has changed the GP's role greatly in recent years; we now play a huge part in supporting people after their cancer treatment has finished.'

Dr Rosie LoftusJoint Chief Medical Officer, Macmillan Cancer Support



END OF LIFE CARE: THEN AND NOW

The end of life care most people experienced at the beginning of the 1970s lacked planning and expertise, but over the years it has become a highly developed field of practice that increasingly puts the patient's needs and compassion at its heart.

The 1970s saw tremendous growth in the number of hospices and palliative care facilities in hospitals across the UK. St. Christopher's Hospice, which was founded is 1967, is widely regarded as an institution that played a key role in developing modern palliative care. Pain management and quality of life became a key focus, and greater emphasis was put on the aesthetic surroundings.

This innovation was slow to make its way into the NHS. Paul Rossi writes in Fighting Cancer With More than Medicine that around this time 'terminal illness was regarded as a medical or surgical failure, and it attracted few of the NHS's resources. Dying patients were cared for in general hospital wards or sent home to die often in great pain and distress. They were rarely given the intensive medical and nursing attention they needed, let alone any psychological and social support'xxi.

An enduring problem from the 1970s to today is the lack of support for people who want to die at home.

GPs and district nurses took on the responsibility for caring for people at the end of life, but usually without any expert palliative care support. Access to round the clock nursing was (as it is today) patchy, and the consequence was that people without the right support and access to pain relief at home would often end up in crisis in hospital, where they would end their days on a general ward. Sadly, many people continue to experience this problem at the end of their life today.

It was not until the mid-1980s that palliative care became an established specialism for consultants, and the 1990s for GPs. In 2000 the Gold Standards Framework (GSF) for primary care at the end of life was developed by a former Macmillan GP and had major investment in its early years from Macmillan it sought to train those working in primary care in the highest standards of end of life care, which would improve consistency and quality of care for people at home and in hospital at the end of life.

The Gold Standards Framework also reflected a broader, important shift in approach where decision making in end of life care shifted from being predominantly undertaken by health care professionals to involving the person with cancer and their family; personal choice and support for carers is now a crucial part of end of life care.

In the summer of 2016 the Department of Health, following campaigning by a number of charities including Macmillan, committed to ending variation in the quality of end of life care experienced by people in England.

In Scotland, the government set out a framework for action on end of life care, which focuses on quality of life for people with life-limiting diseases from the point of diagnosis onwards. In Wales, the Welsh Government's End of Life Care Delivery Plan sets out how patients and their families will be supported at the end of life, providing high-quality care in all settings for people of all ages.



The very first Macmillan services in the 1970s were focused on end of life care, reflecting the poor survival rates of people diagnosed with cancer. These services included the building of 'continuing care units' in hospitals for cancer patients that specialised in palliative care, through to the funding of the very first Macmillan nurses who went out into the community and supported people living with cancer at home.

The number of 'domiciliary' nursing posts funded by Macmillan expanded greatly during the 1980s, reflecting the need for people to be supported outside of the hospital and hospice settings. By the end of the 1980s, there were more than 550 Macmillan nurses working in communities across Britain.

Early Macmillan nurses saw first-hand how the fear of cancer, and even talking about it, meant that many people suffered in silence at home. A Macmillan nurse working in the 1980s recalled: 'Some of the older women who had cancers 'down below' wouldn't even talk about it, the humiliation they felt was too great. I wasn't allowed to take a look to ease any discomfort they were experiencing so they suffered, the stench could be terrible and they died horribly.'

The need for consistent, responsive, good-quality and coordinated end of life care at home is still vital and Macmillan continues to take the lead to achieve this. The Macmillan Specialist Care at Home programme involves a consultant-led team where specialist nurses, support workers and others work together to provide coordinated care to people approaching the end of life in their own home and support for families too.

Based on pioneering work by the Midhurst Macmillan team, the approach reduces the number of people who are admitted to hospital in crisis and increases the number who die in their preferred place. The approach is being tested further in six centres in England and is proving very successful. Macmillan will build on the evidence of what works and spread the learning so more people can benefit.

Ensuring that people with terminal cancer and their families plan ahead is crucial. Advance Care Planning, a process that helps people make important choices and plans for their care before their disease progresses, is vital in ensuring people's dying wishes are made a reality. Macmillan has developed and produced a toolkit for professionals to help them discuss future plans with people before they are unable to make decisions about their own care themselves.

CONCLUSION

Cancer care and treatment has, as we have seen in this report, undergone extraordinary change in the past 40 years. People with cancer are now more involved in important decisions about treatment than they once were, and there is improved recognition of the vital role carers play. Moreover, public perceptions have slowly but surely changed; awareness is better, and cancer is talked about more freely than in the past. A diagnosis, most importantly, is no longer a death sentence for many.

But some things have not changed: frightened and sometimes overwhelmed people are still undergoing an experience that will forever change their and their friends and families' lives.

As our population ages and better treatments are developed, survival rates are likely to improve. This means we will have to become increasingly adept at ensuring people not only get diagnosed and treated quickly, but have a positive experience of care and as good a quality of life as possible throughout and after treatment. We are already seeing more people taking up full and active lives after treatment, with many returning to work.

Today, hundreds of thousands of people with cancer are living with the consequences of yesterday's treatments. In the future, we will have even more people living with cancer in the long term, who are likely to contend with a different set of side effects from today's treatments. We will need to be equipped to deal with this changing story.

Macmillan Cancer Support will continue to meet the challenge cancer poses. Our services have come a long way from the initial five Macmillan nurses appointed in 1975; with the help of our inspirational supporters, we will ensure that over the next 40 years and beyond people with a cancer diagnosis have the best quality treatment and support throughout their cancer journey.

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 This work is part of the Macmillan Cancer Support and Public Health England's NCRAS Partnership Work Plan. The data sourced are presented in collaboration with: the Welsh Cancer Intelligence and Surveillance Unit, the Health Intelligence and Knowledge Management Division, Public Health Wales; the Scottish Cancer Registry; and the Northern Ireland Cancer Registry, which is funded by the Public Health Agency, Northern Ireland.
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Notes

Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.

