

Insights on the experience of people living with cancer and charity supporters today

Introduction

Macmillan is here to do whatever it takes for people with cancer, and to do this well it's important that we gather information about the needs and experiences of people living with cancer from many different perspectives, at both an individual and wider population level. Additionally, Macmillan simply could not function today without the generosity of supporters who give us their time and money.

This summary provides an overview of current key information about people living with cancer from a population level perspective, charity supporters and the wider charitable giving landscape.

It draws on a wide variety of information sources and references knowledge gathered through national representative research about people living with cancer and charity support in the UK.

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The experience of people living with cancer

Key points

- The population's cancer-related needs evolve slowly. The things individuals tell us they'd like more support with have changed little over the last few years despite big changes in the wider world.
- The crisis in the health services and the struggle to improve healthcare performance is leading to increased anxiety amongst people living with cancer about their care. However, many of those most in need are generally seen quickly and effectively.
- Once people are into treatment, NHS pressures are limiting people's access to wider holistic support. This means that more people are likely to have unmet care needs during and after their cancer.
- There is wide variation in experience and outcomes driven by health inequalities, and significant variation in experience and outcomes are seen for different groups of people living with cancer. People with certain types of cancer, long term health conditions and other disabilities in addition to cancer, socio-economic deprivation, and those from ethnically diverse backgrounds all report worse overall cancer experience. The Cost-of-Living crisis is likely to be worsening these issues and we are seeing increased numbers of people needing financial support with rising living costs.

Population context

We estimate that there are currently 3 million people living with a cancer diagnosis in the UK, around 4% of the population. This is projected to rise to 4 million people by 2030. Over a third of these people had their cancer diagnosis 10 years ago or more. Each year around 393,000 people are diagnosed with cancer in the UK, a rise of 40% since 2002.¹

This increase is largely due to the UK's growing and ageing population, meaning there are more people who are at risk of developing cancer. Improvements in cancer diagnosis initiatives, public awareness, and better treatments have also helped those who do have cancer to live longer. The median survival time for cancer (the time after a diagnosis at which half of patients are expected to survive) has increased considerably in recent decades, from one year in 1971-72 to ten years for those diagnosed in 2010-11¹. However, survival rates vary between different types of cancer, the tumour's stage at diagnosis, and a person's sex. For example, for most cancers, survival rates are also poorer for people living in areas of high deprivation than those living in low deprivation areas.

¹ Macmillan Cancer Support, [Statistics fact sheet](#)

Whilst we understand that everyone's experience of cancer is different, at Macmillan we also think about people with cancer as belonging to one of three broad groups who share common experiences²:

1. A **longer-term survival** group, who are usually diagnosed earlier. After treatment they are often cancer free but many live with the physical, practical, financial and/or emotional consequences of their cancer or treatment and can suffer from late effects. They also need to be vigilant about the possibility of cancer coming back. This means the focus of their care is on recovery and long-term quality of life.
2. An **intermediate survival** group, who often have complex and long-term needs more akin to living with a long-term condition. Many people in this group have treatable but not curable cancer. They often have repeated cancer treatments and can feel like they are living from scan to scan. The way people are told that cancer is likely to be life-limiting and the appropriate management of the transition to palliative and end of life care is essential for positive patient experience. People in this group often need a great deal of emotional, physical and financial support. Many face uncertainty every day and have specific personal needs that can change over time.
3. And a **shorter-term survival** group, around half of whom die within a year as a result of their cancer diagnosis. Acute cancer episodes, treatment, and palliative care often dominate the care needs of this group.

Diagnosis

People may follow several routes through healthcare services before receiving a diagnosis, including visiting their GP, attending A&E, or being identified through a national screening programme. There are three main national cancer screening public health programmes; breast, colorectal and cervical cancer³. People at higher risk of these cancers are invited to be tested through these programmes but not everyone takes part and, as a result many people do not find out about their cancer as early as they could which can lead to worse outcomes and lower survival rates for them. Cancer waiting times for diagnosis and treatment in 2022 were the worst on record for each nation in the UK, with some targets having been missed successively for several years.

The repercussions of longer waiting times on people is complex, as those who wait the longest tend to live the longest⁴. This could be because healthcare prioritises dealing with urgent cases and is fastest when providing emergency treatment. This does not mean that outcomes, including experience, are not impacted by the wait.

² Macmillan Cancer Support. [Describing the three cancer groups \(macmillan.org.uk\)](https://www.macmillan.org.uk) McConnell H, White R, Maher J

³ NHSE National Disease Registration Service, [Routes to Diagnosis](#)

⁴ BMJ, Rapid Response to "Mortality due to cancer treatment delay: systematic review and meta-analysis", 2020; [Waiting time paradox in the effects of time to diagnosis or treatment on mortality | The BMJ](#)

The focus on diagnosis targets is diverting resources away from other parts of the cancer pathway and this could be worse for patient experience. As the volumes of people waiting increase, we see increases in anxiety about their care and wait times. Seven in 10 NHS users diagnosed within the last five years say their physical or mental health has deteriorated or they have experienced stress or anxiety about their treatment or care because they experienced delays to their NHS cancer care⁵.

For most types of cancer, people in more deprived areas are more likely to be diagnosed compared to people in less deprived areas (incidence rates of cancer). This is particularly pronounced for lung cancer. Higher diagnosis rates are assumed to be largely attributable to increased risk factors or lifestyle behaviours, such as smoking and obesity.

There are three drivers of health inequalities at diagnosis:

1. Lower screening uptake amongst certain groups⁶
2. Lack of knowledge of cancer signs and symptoms stops people coming forward early enough
3. Barriers to healthcare access mean that once people with symptoms seek medical help they are not always listened to and often have a worse experience

Treatment

NHS pressures are having an impact on cancer care. People report a more complex experience, with appointments cancelled or moved and increased use of remote consultations.

Almost half (48%) of those diagnosed in the last five years have felt stressed and/or anxious about their cancer treatment and care because of waits they have experienced within the NHS⁷. However, many people still feel they personally are being treated quickly and given good care.

NHS pressures and focus on waiting times targets draws staff resources away from the treatment pathway, meaning staff have less time to spend with patients and are perceived to be busier and less available. Due to reduced emphasis on quality care, vital support planning conversations and written plans which are developed from an

⁵ Macmillan Cancer Support, People living with cancer online survey of 2020 adults in the UK who have had a cancer diagnosis. Fieldwork was undertaken between 4 – 28 November 2022. The figures have been weighted and are representative of people living with cancer in the UK (aged 18+). Survey included 277 people who have been diagnosed within the last 5 years and have experienced delays to their NHS cancer care and/or treatment.

⁶Chukwudi Okolie, Amy Hookway, Alesha Wale, Jordan Everitt, Hannah Shaw, Ruth Lewis, Alison Cooper, Adrian Edwards, BMJ, 2022; [A rapid review of barriers and facilitators to cancer screening uptake \(breast, cervical and bowel\) in underserved populations.](#)

⁷ Macmillan Cancer Support online survey of 2076 adults in the UK who have had a cancer diagnosis. Fieldwork was undertaken between 20th March – 8th April 2023. The figures have been weighted and are representative of people living with cancer in the UK (aged 18+). Survey included 243 people who have been diagnosed within the last 5 years and have experienced delays to their NHS cancer care and/or treatment.

understanding of each patient's holistic needs are at risk⁸. Patients often feel that the Holistic Needs Assessment is just another survey for them to fill in (of which they feel they receive too many).

NHS treatment pathways can be complex for some people, meaning that their care is split across multiple hospital sites and, for some new treatments, include an increased role for primary care (GPs and community practices). For those in the **intermediate and short-term survival groups** their treatment options are limited and are more likely to be focused on slowing down and controlling rather than eradicating cancer. Nearly everyone wants more support to help them navigate this complexity.

Inequalities within the NHS also limit treatment options available to individuals. New precision medicines are not evenly distributed across the UK, with access to specialist centres limited by geography and an individual's ability to advocate for themselves. Older people, those from minority ethnic background, or those with different cultural or religious backgrounds report not being listened to, not being treated sensitively, or not feeling confident to challenge healthcare professionals.

Despite these challenges, cancer patients in all four UK nations report high scores for their overall experience of care but experiences vary across different patient groups and for different aspects of their care⁹. For example, patients in England's 20% least deprived areas had the highest score for overall care, whilst patients in England's 20% most deprived areas had the lowest score, and respondents from white ethnic backgrounds gave a higher average rating of care than respondents from Mixed, Asian, and Black ethnic backgrounds¹⁰. In Scotland over a quarter of people (27%) didn't completely understand the explanation of what was wrong with them, and over a third (37%) were not given written information about the type of cancer they had⁹.

Life after cancer treatment

For those whose treatment is successful, the impact of cancer can be long-lasting. People living with cancer across the UK and internationally report lower quality of life in comparison to the general population¹¹.

Lack of prehabilitation and rehabilitation services can mean that people have unmet needs after their treatment finishes. However, in England less than half felt they received the right amount of support from their GP practice and only 18% of patients

⁸ Macmillan Cancer Support, [Cancer nursing on the line - report](#)

⁹ Macmillan Cancer Support, [Cancer experience](#)

¹⁰ NHS England and Picker, National Cancer Patient Experience Survey Results, 2021; [Current results - National Cancer Patient Experience Survey \(ncpes.co.uk\)](#)

¹¹ Macmillan Cancer Support, [Throwing the Light On the Consequences of Cancer and its Treatment](#)

reported having a review of cancer care by their GP¹². In Scotland and Wales larger proportions of patients feel GP practices gave them enough support^{13,14}.

Just under a quarter of people reported poor emotional wellbeing after cancer diagnosis¹⁵. Once out of the treatment pathway patients can find accessing psychological support even more challenging. People often report that after treatment finishes their support 'falls off a cliff'.

Sleep problems and fatigue are two of the most common issues reported by patients after treatment finishes. We know that the NHS struggles to provide comprehensive and effective support for these issues.

After treatment ends some patients in England enter personalised stratified follow up (PSFU) pathways. We are seeing that people are having their needs met in a timelier manner and are better informed about their disease, treatment, signs of recurrence and any longer-term effects. With an increased focus on health and wellbeing, they are being supported to make healthier lifestyle choices and better manage their care¹⁶.

End of life

Around 167,000 people died from cancer in the UK in 2019. Deaths from cancer have risen by 7% over the last 10 years, just under half the increase in cancer diagnoses at 19%.¹⁷

There are some key challenges in palliative and end of life care experience today:

- Inadequate support for people to die in their preferred place of death, which is often at home.
- Challenges to talking openly about death and planning for dying, which mean that advanced care planning discussions are less likely to happen.
- Lack of awareness about end-of-life services and how to get the right support, particularly for marginalised communities.
- A need for more resources and support in emergency departments to support people at end of life who are using emergency care.

¹² NHS England and Picker, National Cancer Patient Experience Survey Results, 2021; [Current results - National Cancer Patient Experience Survey \(ncpes.co.uk\)](https://www.ncpes.co.uk)

¹³ Wales Cancer Patient Experience Survey 2021/22 [Wales-Cancer-Patient-Experience-Survey-results-in-English \(macmillan.org.uk\)](https://www.macmillan.org.uk)

¹⁴ Scottish Cancer Patient Experience Survey 2018: national report [Scottish Cancer Patient Experience Survey 2018: national report - gov.scot \(www.gov.scot\)](https://www.gov.scot)

¹⁵ Macmillan Cancer Support, [Throwing the Light On the Consequences of Cancer and its Treatment](https://www.macmillan.org.uk)

¹⁶ Macmillan Cancer Support, [Cancer experience](https://www.macmillan.org.uk)

¹⁷ Macmillan Cancer Support, [Statistics fact sheet](https://www.macmillan.org.uk)

The experience of charity supporters now

Key points

- In the UK's not for profit sector, supporters interact with charities by making voluntary donations in response to fundraising campaigns, participating in events, leaving gifts in their wills, through volunteering their time or networks, and through campaigning on behalf of causes they support.
- The year-on-year trend for charity fundraising income remains stable, however, the sector is relying on a smaller pool of supporters who are giving more each year to maintain the same position. Also, the biggest charities continue to grow bigger, and they receive an increasing amount and share of the sector's total income.
- Cancer care and research remains a cause that many people care about due to personal connections. However, cancer can be perceived as well funded and proximity to the cause doesn't always translate into giving behaviour.
- People support charities for a combination of reasons. Besides their connection to the cause, they could be motivated by a sense of belonging, a desire to help others, and a feeling of accomplishment. Providing great experiences that meet the different needs of those who choose to support Macmillan, helps build and maintain loyalty to our cause.
- People increasingly want to get involved with charities in different ways and to feel their support has a tangible impact. While fundraising remains the most common way people engaged with charities, we see a decline in volunteers and more young people engaging with campaigning. To grow or even sustain fundraising income, charities must diversify their offerings to better meet the changing needs and expectations of supporters.
- Overall, how people support charities is changing, in terms of the activities they do as well as their motivations and expectations.

Charity support in the UK

It is estimated that people in the UK gave £12.7bn to charities in 2022, an increase from £10.7bn in 2021 and surpassing 2020's estimate of £11.3bn.¹⁸ While the increase might partly be driven by the crisis in Ukraine, where we have seen outpouring generosity from the public, overall charity income is still higher in 2022 than pre-pandemic levels (2018 – 2022)^{18,19}. However, the current cost of living crisis and inflation mean that, while some donors increase the amount donated to adjust for inflation, others are considering cutting donations to charity to manage their bills and so the spending power of the current giving is eroded in real terms¹⁸.

¹⁸ Charities Aid Foundation, UK Giving Report, 2023; [CAF UK research hub | Charitable giving across the UK \(cafonline.org\)](#)

¹⁹ Wood for Trees, State of the Sector Report, 2023; [Reports - Wood for Trees](#)

Furthermore, analysis has shown that while there is an overall upward trend in total UK giving, this is driven by existing donors increasing the amount donated or sponsored, and not a result of more people giving. In fact, the total number of people supporting charities in the UK is in decline, with 84% of people reporting they took part in at least one charitable activity in 2022, lower than pre-pandemic levels (88% in 2019)¹⁸.

The Covid pandemic caused a notable shift in how people choose to do good and engage with charities and has accelerated some emerging trends. People's lives and priorities changed, either temporarily or permanently, with many people changing working patterns and locations and saying they wanted to prioritise time spent with friends and family over material goods. Many charity supporters have developed a greater connection to their local area, and this impacted the causes they supported, as well as where and how they wanted to engage in fundraising activities. Alongside these changes in behaviour, attitudes have also shifted with trust in charities falling²⁰. To sustain or even grow fundraising income, charities must diversify their offerings to better meet the changing needs of supporters.

The cost of living crisis has further prevented overall charity support from recovering to pre-pandemic levels. Some existing charity supporters have needed to or foresee that they will need to reduce their charity donations. Some also say they would prefer to give time over money, although they are often time-poor. The cost of living impact on fundraising is already being felt by charities; particularly towards the end of 2022, during which overall charity income was 14% lower than for the same period the previous year¹⁹. However, larger charities are generally coping better with the impact of the cost of living crisis; 32% of charities reported an increase in their overall voluntary income in 2022 and they are more likely to be larger charities with >£10m income²¹.

Though the cost of living pressure has brought down the number of donors, the number of people feeling worse off is starting to decrease. Spring 2023 is the second quarter in a row where this has dropped; in Autumn 2022 64% of people were feeling worse off, compared to 63% in Winter 2022 and 59% in Spring 2023²². This means that to survive in an increasingly competitive charitable giving market, it is ever more important for charities to demonstrate their relevance and impact, both in terms of individual impact of the supporter and the impact of the charity to the cause it serves. Charities will also need to be ready to engage with potential supporters or re-engage those who suspended their support as cost of living pressure slowly eases over the next 12- 24 months.

²⁰ Macmillan Cancer Support/BritainThinks, Internal research "The Changing Doing Good Landscape", 2022

²¹ Blackbaud, The Status of UK Fundraising 2022 benchmark report, 2022; [the-status-of-uk-fundraising---2022-benchmark-report.pdf \(cms.blackbaudcdn.net\)](#)

²² Enthuse, Donor Pulse Spring, 2023; [Donor Pulse Spring 2023 - Enthuse: Branded fundraising for charities](#)

Which causes do people support?

Cancer remains one of the top causes supported in the UK. Macmillan routinely comes out top in surveys that look at the most popular brand, overall support/donations, or best loved UK charities, often tracking alongside Cancer Research UK^{23,24}. However, other causes like animal welfare and children and young people are also very popular. In 2022 we saw an increase in support for overseas aid and disaster relief, driven by the public response to the war in Ukraine.

While cancer is a relatable cause, with almost everyone having a close or distant personal connection to it, it is a cause that can be perceived as well-funded. Our research shows that two-fifths (40%) of UK adults say cancer is the main cause they care about, but only about one in five (18%) said they would consider giving to Macmillan²⁵.

Most charity supporters support more than one charity, with 93% reporting giving to two or more charities in the last 12 months²⁶. Most Macmillan supporters also support Cancer Research UK, British Heart Foundation, Marie Curie, and the Royal British Legion also share supporters with Macmillan.

Charitable support is a competitive marketplace, but cancer as a cause is well positioned to deepen its connection with potential and existing supporters who care about preventing cancer and improving the quality of life for those who are diagnosed. It is crucial that cancer charities build and increase supporter loyalty by providing great experiences that meet the differing needs of their supporters.

Who supports charities and why?

Although charitable support in the UK is high, there are noticeable differences across demographics. Charity supporters are more likely to be female across all types of support: donating money (58% women vs. 49% men), campaigning (e.g. signing a petition, 50% women vs. 43% men), and volunteering (14% women vs. 11% men)²⁷.

People of all ages engage in charitable activities, but this behaviour is more apparent in older age groups. 95% of those aged 65+ reported doing at least one act of charitable support in the past 12 months, compared to 76% of those aged 18-24²⁷. Older charity supporters are also most likely to continue to support the same charity over time,

²³ Savanta, Macmillan, Cancer Research UK, and Dogs Trust are UK's most loved charities, 2023; [Macmillan, Cancer Research UK, and Dogs Trust are UK's most loved charities - Savanta](#)

²⁴ YouGov, The Most Popular Charities and Organisations (Q1 2023), 2023; [The most popular charities & organisations in the UK | Politics | YouGov Ratings](#)

²⁵ Macmillan Cancer Support, Internal Brand Health Tracker Quarterly Reporting Q1 2023, 2023

²⁶ Blackbaud, Donor Behaviour Insights, 2023; [mf-2023-02-07-tl-rp-donorinsights.pdf \(cms.blackbaudcdn.net\)](#)

²⁷ Charities Aid Foundation, UK Giving Report, 2023; [CAF UK research hub | Charitable giving across the UK \(cafonline.org\)](#)

compared to younger audiences who are influenced by their peers and will often give based on what appeals to them at the time²⁸.

For most supporters (99%) the motivation to give is largely driven by a sense of duty to give back or tackle inequality. This is followed by those motivated to give through belief in a specific cause. This belief can be based upon having a specific passion (75%) such as the arts, or by a personal connection to a cause (61%)²⁹. This connection can be either through directly experiencing a charity's help or seeing a loved one supported. We know that in Macmillan £7 in £10 of our income is directly inspired by the support we are seen and known to provide for people living with and affected by cancer.

While giving motivations usually remain the same, we have seen a shift in how some groups of supporters engage with charities post-pandemic. For example, those who used to prefer supporting charity via donations pre-pandemic, now appear more willing to take part in challenge events and enjoy organising fundraising activities themselves³⁰. This understanding of supporter motivations and changing charitable behaviours allow us to engage with them in ways that meet their needs and expectations and retain their vital support.

How people support charities

We think about charity support in 3 broad areas: fundraising, volunteering and campaigning.

Fundraising

Fundraising refers to charitable activities where people donate money, donate goods, organise fundraising events, take part in fundraising challenges, or sponsor a fundraising event or challenge. It is the main way people support charities; 54% of UK adults have donated money to charity in the last year, 51% have given goods, 23% have sponsored someone and 7% had fundraised themselves for a charity³¹.

Most fundraising methods saw a fall in new supporters in 2022. The exception to this was regular giving (i.e. monthly donations via Direct Debit) which grew both in terms of income as well as new supporters, who are increasingly from younger and less affluent demographics. The long-term retention of these new supporters may be increasingly difficult given the wider economic context³².

²⁸ Blackbaud, Donor Behaviour Insights, 2023; [mf-2023-02-07-tl-rp-donorinsights.pdf](https://cms.blackbaudcdn.net/mf-2023-02-07-tl-rp-donorinsights.pdf)
cms.blackbaudcdn.net)

²⁹ Charities Aid Foundation, Why do people make donations to charity | 4 reasons why we give | CAF (cafonline.org), 2023; [Why do people make donations to charity | 4 reasons why we give | CAF \(cafonline.org\)](#)

³⁰ Macmillan Cancer Support, Supporter Summary, 2022

³¹ Charities Aid Foundation, UK Giving Report, 2023; [CAF UK research hub | Charitable giving across the UK \(cafonline.org\)](#)

³² Wood for Trees, State of the Sector Report, 2023; [Reports - Wood for Trees](#)

While we have seen supporter recruitment fall, in 2022 the volume of funds raised via JustGiving, by individual fundraisers who organised their own events, grew by over 10% from 2021, reaching 23,000 charities³³. This shows the vast potential in individual fundraising, even in the face of cost of living pressures.

Campaigning

Campaigning is another popular way for people to show support to a charity or a good cause. 47% of UK adults aged 16+ reported signing a petition in 2022. While this is a decline from 2019's report of 54%, campaigning is a valuable way to engage with younger supporters; in 2020 the 16–24 age group were the most likely to have signed a petition (35%) 1 and 1 in 6 charity supporters aged 18-34 show their support through activism³⁴.

Volunteering

Participation in volunteering activities has declined in recent years. Around one in ten UK adults volunteered in 2022 (13%), lower than pre-pandemic levels (16% in 2018 and 2019)³⁵. This represents around 1.6 million fewer people volunteering compared to five years ago. Likelihood to continue volunteering amongst recent volunteers has also declined slightly from 80% in 2018 to 77% in 2022³⁶.

Since the pandemic, technology has played an increasingly important role in volunteering. Virtual volunteering (volunteering online or over the phone) is now the third most common way to volunteer. 31% of those who volunteered in 2022 did at least some of it virtually³⁷, compared to 16% in 2018³⁸. Volunteer satisfaction is nearly equal among those who did all their volunteering virtually (95% satisfied) and those who volunteered face to face (93% satisfied)³⁷. This signals that the shift from face to face volunteering to hybrid or virtual volunteering is likely to stay, as it gives good volunteer experience if done right, and could even expand to help drive volunteering uptake.

³³ Blackbaud, Donor Inspiration to Boost Fundraising, 2023; [mf-2023-04-04-tl-eb-givingfocus.pdf \(cms.blackbaudcdn.net\)](#)

³⁴ Blackbaud, Donor Behaviour Insights, 2023; [mf-2023-02-07-tl-rp-donorinsights.pdf \(cms.blackbaudcdn.net\)](#)

³⁵ Charities Aid Foundation, UK Giving Report, 2023; [CAF UK research hub | Charitable giving across the UK \(cafonline.org\)](#)

³⁶ Wood for Trees, State of the Sector Report, 2023; [Reports - Wood for Trees](#)

³⁷ NCVO, Time Well Spent, 2023; [Key findings from Time Well Spent 2023 | NCVO](#)

³⁸ NCVO, Time Well Spent, 2018; [Introduction - Time Well Spent: A national survey on the volunteer experience | News index | NCVO](#)