

**Cancer:**  
Out of   
**Sight** **NOT**  
Out of   
**Mind**

**All.Can UK:**  
Placing the psychological  
wellbeing of people with  
cancer on equal footing  
to physical health

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## About **All.Can** UK

In the UK, All.Can is a partnership between leading health charities and biopharmaceutical companies with a shared ambition for cancer patients to receive world class, patient centred care that is sustainable for the NHS to deliver.

All.Can UK is a multi-stakeholder initiative involving patient group and industry experts. In the UK, All.Can is funded by Bristol Myers Squibb (primary sponsor) and MSD (supporting sponsor). All.Can International is a not-for-profit organisation (ASBL) registered in Belgium. Its work is made possible with financial support from Bristol Myers Squibb (main sponsor), Roche (major sponsor), MSD and Johnson & Johnson (sponsors), Baxter and Illumina (contributor), with additional non-financial (in kind) support from Helpsy, Intacare and Goings-On. All.Can is a registered trade mark of All.Can International.

All.Can UK is chaired by The Patients Association, a leading national charity which is dedicated to supporting the rights and interests of all patients and their families. The initiative brings together a collaborative Working Group of health charities to identify the current inefficiencies facing cancer services in the UK and to develop recommendations to help improve patient care through best practice implementation and long-term thinking. If you would like more information on All.Can UK, please visit our website at: <https://www.all-can.org/national-initiatives/uk/>

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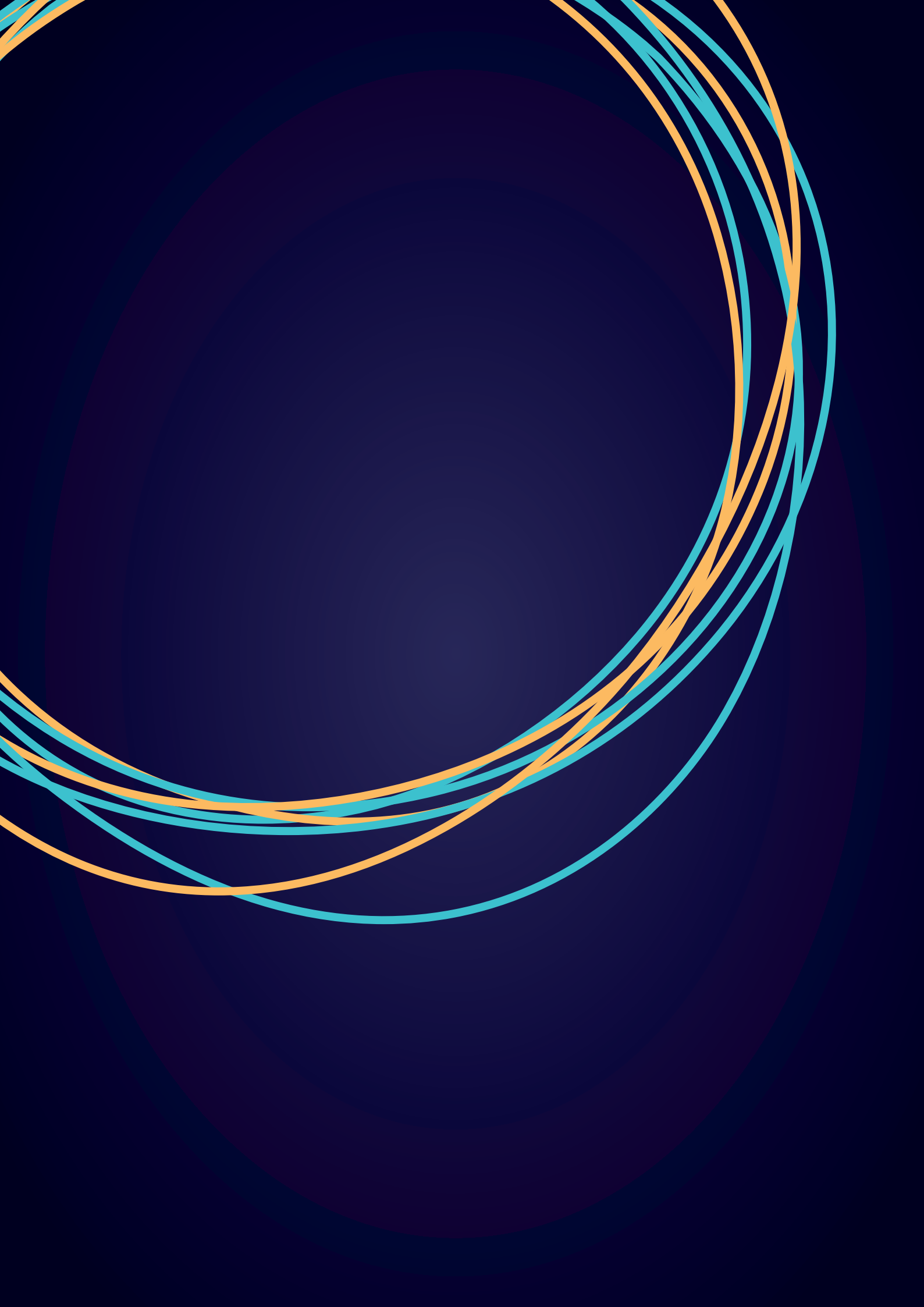
## Acknowledgements

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- The Patients Association, Chair of All.Can UK
- The following health charities who gave oral evidence:
  - Blood Cancer UK
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  - British Liver Trust
  - Fight Bladder Cancer
  - Maggie's
  - Melanoma UK
  - MSD
  - Shine Cancer Support
  - The Urology Foundation
- Professor Michael Sharpe, Professor of Psychological Medicine, University of Oxford
- Almost 4,000 cancer patients and caregivers from more than 10 countries, who responded to the All.Can global patient survey.

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# Foreword

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Supporting people with cancer is a major priority for the NHS and it is promising that the link between mental health and cancer is now well understood amongst clinicians, policymakers and the third sector. However, from the evidence gathered throughout the development of this report, it is clear how difficult it still is for people with cancer to access this vital support.

Ensuring the psychological and emotional wellbeing of patients is seen as equal to that of their physical health has never been more important. COVID-19 has placed untold pressure on cancer services across the UK and has significantly impacted the psychological wellbeing of people with cancer, with delays in diagnosis and treatment regimes resulting in increased anxieties for patients and their families.

As the Chief Executive of the Patients Association, I deeply appreciate the vital role the patient group community plays in supporting patients throughout their cancer journey, which has been made all the more important as a result of the pandemic. As this report demonstrates, there is a large range of psycho-social interventions that are offered by the third sector to people with cancer. Yet, the current NHS cancer pathway is not as efficient in promoting psychological wellbeing and treating co-morbid mental health conditions as it should be. Moreover, COVID-19 has already had a significant impact on All.Can UK's health charity members' ability to offer psychological support services due to reduced funding flows and huge increases in demand. The

long-term impacts of COVID-19 will likely only exacerbate this in the future.

I hope that the examples in this report highlight how barriers can prevent patients from receiving the care they need. All.Can UK is now calling on policymakers, the NHS, industry and fellow patient organisations to work with us to take forward the recommendations included within this report in order to bring about much-needed change for patients. It has been an eye-opening experience to hear from our Working Group members about the life-changing support they offer to people with cancer, and the challenges that patients can face in accessing these services.

I would like to take this opportunity to thank everyone who contributed to this report and look forward to working collaboratively with you to make these recommendations a reality.



**Rachel Power,**

CHIEF EXECUTIVE OF THE  
PATIENTS ASSOCIATION  
CHAIR OF **ALL.CAN UK**

NOVEMBER 2020



# Executive Summary

The link between mental health and cancer is well understood, with around one in four cancer patients requiring expert psychological assessment and intervention as a result of their diagnosis.<sup>1</sup> However, there are many reasons behind this correlation, and how cancer affects an individual's mental health is unique. For some, receiving a cancer diagnosis can be psychologically distressing;<sup>2</sup> for others, it could be the symptoms of cancer or the side effects of their treatment.<sup>3</sup>

While the NHS has already taken steps to expand the availability of mental health services, there is significant unmet need and the increasing number of patients who are expected to survive cancer<sup>4</sup> means that there could be a growing demand placed on the health service to provide support to patients.

In order to gain a deeper understanding of inefficiencies in cancer care, and what must be done to ensure patients receive the psychological support they want and need, All.Can UK gathered evidence from several health charities and expert academics to inform this report.

The evidence gathered uncovered a number of barriers that patients face in accessing mental health support and examples of best practice across the NHS and voluntary sector in providing it. Key themes centre around the lack of awareness within the NHS oncology workforce about patients' needs in relation to mental health, as well as the resources and services that are available. There is also little understanding of the role that the third sector and health charities play in supporting patients' mental health and ensuring that the care they receive is not 'one size fits all'. Furthermore, additional challenges exist around variation in access to care and the availability of mental health screening for cancer



**One in four cancer patients requires expert psychological assessment**

patients, which results in their needs not being properly addressed.

These issues were identified before the COVID-19 pandemic became widespread across the globe. However, it is well documented that infectious disease outbreaks, like coronavirus, can affect mental health.<sup>5</sup> In particular, the delays in cancer screening, diagnosis and treatment regimens that have been caused by the COVID-19 pandemic have placed further strain on individuals' psychological wellbeing.<sup>6</sup> As such, it is more important than ever that people living with cancer are offered psychological support and regular touchpoints with healthcare professionals to ensure they are receiving effective support throughout their care journey.

As a result, there is a need for the NHS and the wider oncology community to come together and address the unmet need in service provision for mental health care in cancer patients, which has been further exacerbated by the COVID-19 pandemic. In support of this, All.Can UK makes the following recommendations:

## RECOMMENDATIONS

- 1.** NHS Trusts should mandate training and increase support so that all members of multi-disciplinary cancer teams, including Specialist Cancer Nurses (SCNs) and surgeons, are fully trained to the tier 2 standard of NICE's four-tier model of psychological support.
- 2.** Following a cancer diagnosis, patients' mental health needs should be assessed at the earliest possible opportunity. Screening should also take place at regular milestones, including 6 and 12 months post-diagnosis, so that issues can be identified and acted upon, throughout and beyond a person's cancer journey.
- 3.** NHS England, in collaboration with the patient group community, should raise awareness within the oncology workforce to ensure they are aware of the entire range of psycho-social interventions offered by the third sector.
- 4.** The NHS should take steps to personalise psycho-oncology services and avoid 'one size fits all' approaches in line with NHS England's ambition to increase access to personalised care. NHS staff should ensure patient group materials are made available to oncology patients so that they are aware of the mental health support that they can receive.
- 5.** The Government and NHS England should work to address the regional variation in access to mental health support for patients with cancer. To support this, the NHS Mental Health Dashboard should be expanded to include specific data on cancer and mental health conditions so that the NHS can have a better understanding of the level of patient need for services.

# All.Can UK survey

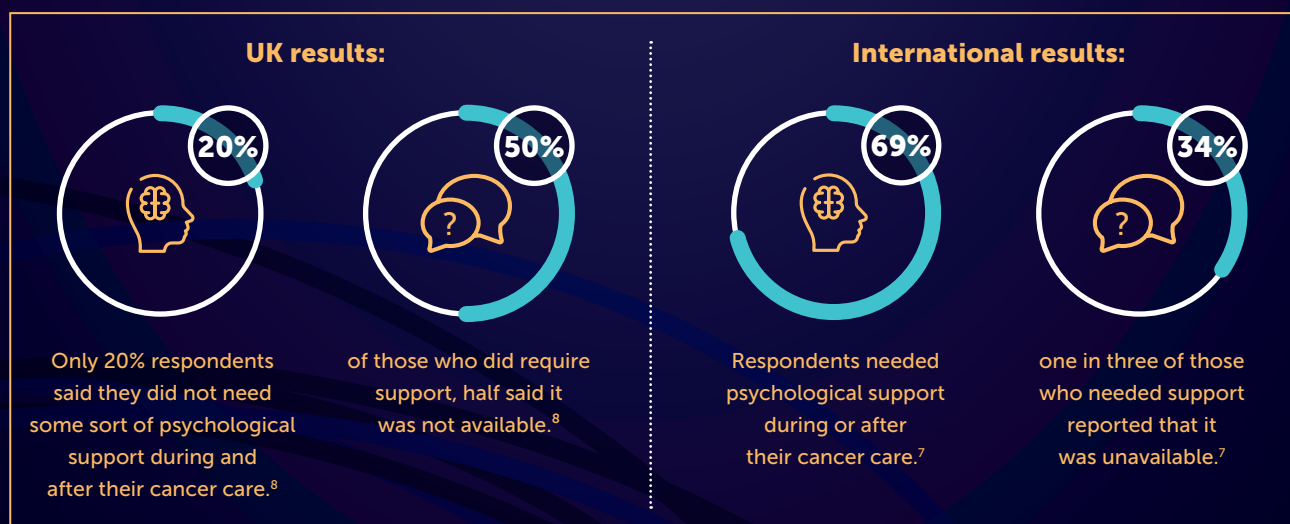
In 2018, All.Can commissioned an international survey to explore patients' experiences of cancer care and understand their priorities for how services could best support patients' needs. The international survey gathered experiences from almost 4,000 cancer patients and caregivers from more than 10 countries. While most people reported that the majority of their needs were sufficiently addressed during their care, there were specific areas where people often encountered inefficiency. This included psychological support.

In the international results, the majority of respondents (69%) said they needed psychological support during or after their cancer care, yet one in three (34%) of those who needed such support reported that it was unavailable.<sup>7</sup>

The UK results of the survey, representing 322 people, indicate that there is considerable unmet need in the provision of psychological support services:

- Only 20% respondents said they did not need some sort of psychological support during and after their cancer care.<sup>8</sup>
- Of those who did require some support, half said that it was not available.<sup>8</sup>

It is positive that 79% of those people who did access psychological support said that they found it quite or very helpful.<sup>8</sup> However, the consequences of not meeting psychological support needs remain far reaching. Evidence suggests that individuals experience worse physical and bodily symptoms, poorer quality-of-life and a desire for hastened death.<sup>9</sup> It is therefore clear that there is a strong argument for psychological support being routinely offered to patients with cancer to, where possible, avoid or mitigate these concerns.





# Understanding the mental health impact of cancer

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In England, one in six people report experiencing a common mental health problem, such as anxiety and depression, in any given week.<sup>10</sup> For people with cancer, one in three will experience a mental health problem such as depression or anxiety disorders before, during or after treatment<sup>3</sup> and around one in four cancer patients will require expert psychological assessment and intervention as a result of their diagnosis.<sup>1</sup>

## Correlation between cancer and mental health

Although it is well established that psychological distress in cancer patients is a significant and ongoing problem,<sup>11</sup> the reasons for the correlation are complex and varied.

For some, receiving a cancer diagnosis can have a significant psychological impact on them. For others, it can be the associated symptoms of cancer or the side effects of treatment that have a serious impact on their mental wellbeing.<sup>12</sup> These symptoms and side effects include, fatigue, nausea, hair loss, sexual dysfunction, pain and weight gain/loss.<sup>12</sup> The consequence of these effects can be a change in appearance, isolation, fear, or a loss of independence, control, identity and self-esteem – all of which can be detrimental to mental wellbeing.<sup>12</sup>

With the number of patients who will survive for five years or more following their cancer diagnosis continuing to grow,<sup>4</sup> patients will increasingly experience cancer as a long-term condition. Evidence shows that physical long-term health problems and poor mental health are correlated and exacerbate each other.<sup>13</sup>

Furthermore, many cancer survivors have to live with the consequences of treatment, some of which can be life changing. Some cancers, such as head and neck, can carry a long-term post-treatment burden such as difficulties in swallowing or speaking. This can have a lasting and significant impact on quality of life and mental health.<sup>14</sup>

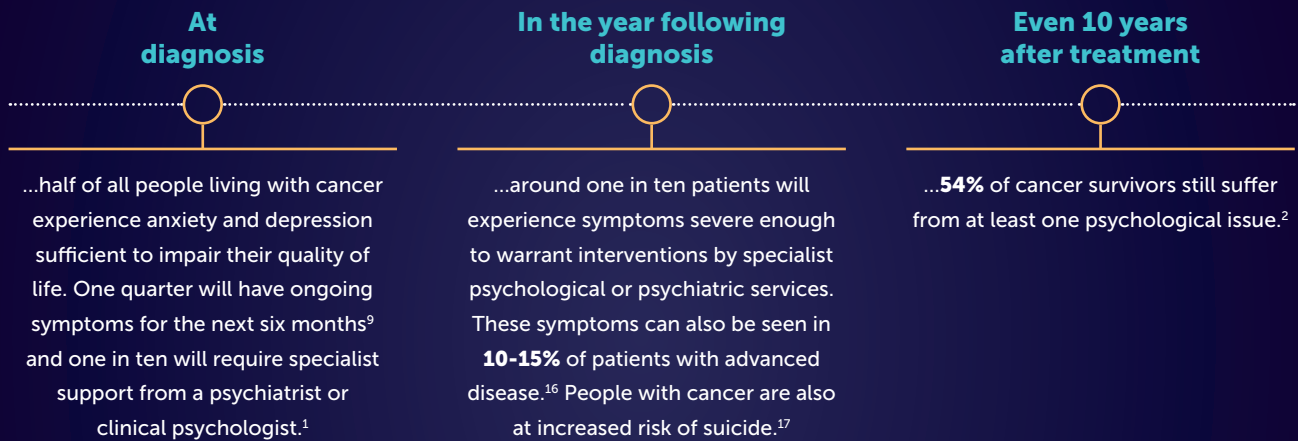
How cancer affects an individual's mental health is unique to every individual. However, the groups identified as being at a higher risk of suffering psychological and emotional problems as a result of a cancer diagnosis are women; parents with young children; people with co-morbidities; and those from poorer backgrounds.<sup>2</sup> A 2019 report by Macmillan Cancer Support demonstrated that whilst many of the people living with cancer in the UK are not getting the emotional or mental health support they need, those living in the most deprived areas are even less likely to have these needs met.<sup>15</sup> The report states that those on lower incomes are more likely to express a need for additional support around issues such as sadness and depression, as well as for practical support both inside and outside the home.<sup>15</sup> Recognising the extent of support needed by the most deprived (and hard to reach) groups of patients will be vital to ensuring equitable access to psychological and wellbeing support.

These factors have been further exacerbated as a result of the COVID-19 pandemic. The outbreak has made many people feel vulnerable and overwhelmed, especially those who have longer-term physical health conditions, such as cancer, and have experienced mental health problems.<sup>5</sup> Furthermore, the pandemic created huge

interruptions to cancer services in the UK, including delays in referrals, diagnosis, treatment and clinical trials.<sup>6</sup> As a result, people with cancer have felt anxious and distressed.<sup>6</sup> Whilst the full impact of the pandemic is not yet known, it is already clear that psycho-oncological support for people with cancer will be more important than ever.

## Timeline of effect

A mental health issue can occur at any time during a person's cancer journey:



## Economic cost

### The psychological impact of cancer is also costly. Neglecting psychological problems exacerbates illness and increases health care costs.

Not only do comorbid psychological distress and psychiatric disorders worsen a person's health outcomes, they also increase the costs for the health service associated with long term conditions by up to 45%.<sup>18</sup> When the emotional needs of cancer patients remain unresolved, they are more likely to use community health services, visit their GP and spend more time in hospital.<sup>2</sup>

There is also a personal financial impact of cancer. Over four in five patients with cancer incur a financial burden, including spending on central heating and transport visits.<sup>19</sup> Furthermore, 27% of UK respondents to All. Can's survey stated that loss of employment due to their cancer care and treatment had had a financial impact,<sup>8</sup> and even those who remain in work have more time off sick which may impact household finances.<sup>2</sup>



Over four in five patients with cancer incur a financial burden, including spending on central heating and transport visits.<sup>19</sup>

These findings were echoed in a report by Demos, which found that over 80% of people with cancer experienced a financial loss of £570 a month. To make matters worse, the cost of cancer is not evenly spread across cancer types and affects those diagnosed with certain types of cancer such as lymphoma, leukaemia, and testicular and brain cancers more than other types.<sup>19</sup> Demos reported in 2019 that the total economic cost of cancer to the UK economy in terms of lost wages and benefits is at least £1.4 billion a year, rising to £7.6 billion a year when mortality is taken into account.<sup>20</sup>

Aside from the financial implications, being out of work is also a known risk factor for poorer mental health outcomes,<sup>21</sup> with financial worries compounding patients' stress levels. Research undertaken by Bristol University found that almost 18% of people with cancer felt they faced a constant struggle when trying to keep up with the payment of the bills accrued as a consequence of cancer.<sup>22</sup>

These figures demonstrate the severe financial impact of cancer, without taking into account the additional impact on family, friends, careers and businesses.

# What does the current pathway look like?

The type of intervention a patient needs usually depends on the nature and severity of their psychological condition, their mental health history and the status of their cancer.

Support typically offered within the NHS falls into two categories:

1. Support that is provided by a healthcare professional, who does not specialise in mental health but who has undergone training in assessing and treating mental health conditions, known as **'tier 1'** and **'tier 2'** support.

2. Support that is provided by a trained mental health/psychological support professional, known as **'tier 3'** and **'tier 4'** support.

NICE has also approved a four-tier model of psychological support, acknowledging that different treatment types are more effective at different stages:<sup>2</sup>

Tier	Who should provide it?	What should be assessed?	What is the intervention?
1	All health & social care professionals	Recognition of psychological needs	Effective information giving, compassionate communications and general psychological support
2	Health & social care professionals with additional expertise (including Cancer Nurse Specialists)	Screening for psychological distress	Using standardised screening tools e.g. the Distress Thermometer, Hospital Anxiety and Depression Scale etc.
3	Trained and accredited professionals	Assessments for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit therapeutic framework
4	Mental Health Specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy



Around 65% of people with cancer access support at levels 1 and 2 within the NICE model, which are appropriate for the majority of people and can act to prevent anxiety and depression developing into more severe clinical conditions. However, around 10% will need a higher level of psychological support.<sup>12</sup> These kinds of interventions take place at different points during a patient's journey, most typically after diagnosis, immediately post treatment and end of life.<sup>2</sup>

To consistently deliver interventions from level 1 to 3, NHS England developed the Improving Access to Psychological Therapies (IAPT) programme. IAPT is a programme of talking therapies designed to help people to overcome their depression and anxiety, and better manage their mental health. The evidence-based psychological therapies are measured by routine outcome monitoring and offered by fully trained practitioners who undergo regular supervision.<sup>23</sup>

Commitments set out in the NHS Long Term Plan state that the number of people with anxiety disorders or depression who can access talking therapies through IAPT will increase by an additional 380,000 per year to reach 1.9 million by 2023/24.<sup>23</sup> NHS England is calling this *"the most ambitious programme of talking therapies in the world"*.<sup>23</sup>

With a pathway in place and IAPT being invested in and expanded, there seems to be a strong foundation of support for patients with cancer and mental health needs. Yet half of UK patients in the All.Can survey could not access services they needed.<sup>8</sup> To improve access and to ensure cancer patients benefit from the ambitions set out in the Long Term Plan, we need to explore the key barriers to accessing mental health and psychological wellbeing support in the UK.

*NICE has also approved a four-tier model of psychological support, acknowledging that different treatment types are more effective at different stages*

# Barriers to accessing mental health and psychological wellbeing support

Despite a clear pathway being in place for patients to access appropriate mental health support, the All.Can survey and additional evidence from the health charities within All.Can UK's Working Group demonstrate that patients with cancer are not receiving access to these interventions at the appropriate time.

## NHS staff resource and awareness

Many psychosocial oncology departments are "understaffed, under-funded and uncoordinated".<sup>2</sup> This could be why, as one All.Can UK Working Group member pointed out, it is not uncommon for healthcare professionals to fail to inform patients of the psychological support available to them within the NHS, despite the patient showing signs of needing support or – in some cases – asking for it directly. They said:

*"Patients have told me that they've asked their oncologist for advice on how to look after their mental health and they say 'I don't know.' Another patient recently told me that no one mentioned to them about getting psychological support".<sup>24</sup>*

NHS staff often provide world class cancer care for a patient's clinical and physical needs, but All.Can's health charities felt that a lack of staff time in both primary and secondary care means healthcare professionals, including General practitioners (GPs), Specialist Cancer Nurses (SCNs), oncology consultants and surgeons, are not adequately sign-posting patients to psychological support.<sup>24</sup> In many cases,

appointment times are short and focus on a person's physical health and treatment plan; issues that are critical to survival. As a result, emotional wellbeing is typically not discussed.<sup>12</sup>

The ability for staff to assess a person's mental health needs can also be hindered by a lack of training. Macmillan Cancer Support has stated that health and social care professionals often lack appropriate assessment skills to identify mental illness and may underestimate the benefits of psychological support.<sup>2</sup> If the training given to tier 2 professionals, outlined in NICE's 4-tiered model of psychological support, was expanded to tier 1 professionals (which includes oncologists and haematological staff), then all members of cancer multidisciplinary teams (MDT) would be equipped to screen for psychological distress. To achieve this, there must be an increase in resource to rejuvenate training and ensure it is sustainable.

Specialist Cancer Nurses are a particularly critical workforce group for all patients, acting as a 'key worker' throughout diagnosis, treatment delivery and palliative care.<sup>25</sup> Often, they provide guidance and direction in the provision of care, act as a resource to others and empower the person with cancer. They make a valuable contribution to the quality and effectiveness of cancer care and are particularly valued by patients affected by cancer.<sup>26</sup>

Furthermore, a survey conducted by Lung Cancer Nursing UK between May and July 2019 found that the majority of Lung Cancer Nurse Specialists were confident in their ability to provide mental health support for patients.<sup>27</sup>

However, despite the immense value that SCNs bring to patients, there is no nationwide agreement of the standard of expertise or qualifications that are required of them to deliver psychological support to patients.<sup>26</sup> To ensure they can excel in their roles, SCNs need recognition from employers and health service managers and should be provided with time and improved support to seek continuous training opportunities.

Being 'mental health aware' is not just a job for cancer nurses. Steps should be taken to upskill staff across the NHS to ensure that patients throughout the treatment pathway can receive mental health care and support. One organisation advised:

*"Mental health nurses need an understanding of oncology, and oncologists need an understanding of mental health. The whole system has a role to play, and everyone should be a 'mental health first aider.' This will support the integrated care agenda".<sup>24</sup>*

To ensure the full oncology MDT is able to provide mental health screening and support to patients, ongoing training should be resourced by each NHS Trust. Each member of the cancer MDT has different expertise to offer, and it is important that good quality psycho-oncology services can be provided to patients at all stages of the treatment pathway. Additional training would equip all healthcare professionals working in oncology to support patients holistically, addressing both specialists and general challenges.

One particular professional group that would benefit from additional training is surgeons. As one of the first healthcare professionals that patients may see following their diagnosis, they play a crucial role. If surgeons were equipped to proactively make patients aware of psychological wellbeing support services at this early stage, patients could understand what is available to them and be more willing to utilise this support later in their treatment pathway and beyond.

#### **Recommendation:**

*NHS Trusts should mandate training and increase support so that all members of multi-disciplinary cancer teams, including Specialist Cancer Nurses (SCNs) and surgeons, are fully trained to the tier 2 standard of NICE's four-tier model of psychological support.*

### **Lack of screening throughout a patient's journey**

Sometimes, a patient does not realise that they are suffering from anxiety or depression<sup>24</sup> without an intervention from a family member or healthcare professional. It is therefore crucial that patients have their needs assessed early and at regular stages throughout their cancer journey.

However, routine screening of cancer patients for psychological problems is not commonplace; instead, most are self-referred or referred by healthcare professionals who happen to notice their distress during clinical care.<sup>2</sup> The health charities explained that many patients are given information regarding their psychological wellbeing at the point of diagnosis, when it can be hard to absorb anything further than the diagnosis; however, their mental health is not followed up later, especially post-discharge.<sup>24</sup>



One organisation explained:

*“Patients go to their appointments a year later or two years later and not enough attention is given to their psychological and emotional wellbeing. The majority of the time is spent assessing their physical health”.*<sup>24</sup>

The post-treatment phase of cancer care can be one of the most volatile times for mental health and the period where the full psychosocial impacts of cancer and treatment can be felt most acutely.<sup>12</sup> For some, it is a struggle when there is no longer any evidence of the disease and they are effectively discharged from NHS support. Often, they still require mental health support, which is why they remain in peer support groups or in touch with patient groups, as they are still living with the emotional impact of cancer, despite no longer having the disease.<sup>28</sup> However, this is also the time when they receive the least professional support, in contrast to the end of their – usually carefully managed – clinical phase of care.<sup>12</sup> Of the service users interviewed in the Mental Health Foundation Scotland study, all stated that the fact that their mental health could decline after treatment had not been mentioned to them.<sup>12</sup>

To support patients with their psychological wellbeing in recovery, Macmillan Cancer Support and the National Cancer Survivorship Initiative developed the Macmillan Cancer Care Recovery Package in 2013. This included recommendations on key interventions which can better support and improve the quality of life of people living with and beyond cancer. The package included the Holistic Needs Assessment (HNA), which was designed to give patients the opportunity to discuss their emotional, practical, physical and spiritual concerns following a cancer diagnosis<sup>29</sup>

in order to equip healthcare professionals and patients to create a care plan together. In reality, however, All.Can UK’s health charities raised the fact that local variation exists in the implementation of the HNA.<sup>24</sup>

To ensure the Recovery Package is fit-for-purpose, Macmillan have launched ‘Right By You’.<sup>30</sup> This initiative is an evolution of the Recovery Package, which looks to support patients in undertaking a needs assessment and care planning to help them to identify and navigate to the support they need. Importantly, ‘**Right By You**’ recognises the fact that conversations between patients and healthcare professionals regarding a person with cancer’s needs and co-morbidities is an ongoing process.

It is also designed to support patients to feel empowered to talk about their mental health in a way that resonates with them. Members of All.Can UK’s Working Group explained that often, patients do not communicate in terms of the mental health impact of their cancer, including feeling depressed or anxious. Instead, they talk of ‘cancer distress’ or describe the ways their cancer compromises their emotional wellbeing. For example, patients raise the fear of their cancer returning, the difficulty of living with uncertainty, feeling “flat” and overwhelmed, and experiencing relationship difficulties. As such, patients often need to move past a barrier of failing to see these feelings as mental health issues, which in turn impact their holistic care.<sup>28</sup>

It is hoped that the evolved ‘**Right By You**’ initiative will support these discussions across the board and not just in areas of best practice. However, it must be implemented effectively so needs assessments are undertaken at the earliest possible opportunity, reassessed throughout a person’s cancer journey, with steps taken to implement the findings.



### Recommendation:

*Following a cancer diagnosis, patients' mental health needs should be assessed at the earliest possible opportunity. Screening should also take place at regular milestones, including 6 and 12 months post-diagnosis, so that issues can be identified and acted upon, throughout and beyond a person's cancer journey.*

## Lack of awareness and understanding of what the third sector offers

As per the NICE four-tier model of psychological support, people with 'low level' psychological need (tier 1) benefit from effective information giving, compassionate communications and general psychological support.<sup>2</sup> For these patients, access to tailored peer support and information from health charities may be the most effective form of support.

Peer support covers a whole range of activities, from mentoring, coaching and navigation to emotional, social, physical and practical support,<sup>31</sup> which means it can be tailored to a patient's individual needs, and therefore can be highly beneficial. At its core it is a process of exchanging knowledge and support with people going through a similar experience, which can help build resilience and promote wellbeing for both support users and providers.<sup>12</sup>

NHS England refers to peer support as one of the 'slow burn, high impact' interventions that is 'essential' to the future of the NHS.<sup>32</sup> Unfortunately, this emphasis from NHS England has not yet led to care improvements, with 40% of patients who took All.Can's survey reporting not being given any information about patient groups, health charities, peer support groups, or other organisations who could support

them.<sup>8</sup> One charity that All.Can UK interviewed explained that the value of peer and third sector support can be "underestimated".<sup>24</sup>

This lack of understanding stems from low levels of awareness of active peer support groups available, as well as of what types of support these groups offer. For patients to receive the best care there needs to be better signposting in place from service providers who are aware of the range of support mechanisms available.<sup>12</sup>

To address this, many of the health charities that All.Can UK interviewed explained that they undertake various activities to educate healthcare professionals on the services and support that are available.<sup>24</sup> A representative from Kidney Cancer UK explained:

*"We work with large hospitals to ensure that when patients receive a [kidney cancer] diagnosis, they also receive information on Kidney Cancer UK support options at the first touch point. Lack of resources prevent us from talking to even more hospitals".<sup>24</sup>*

To these ends, Fight Bladder Cancer has developed and disseminated nurse contact cards to urological nurses and Melanoma UK places cards in many skin cancer clinics, both of which are designed to raise awareness of these organisations and the support they can offer patients.<sup>28</sup>

To further support healthcare services to be aware of the support the voluntary sector can provide, there needs to be increased communication between all parties, led by the NHS and the patient group community, to enable better service collaboration and more co-ordinated support pathways. It is imperative that NHS organisations partner with the voluntary sector to signpost people living with cancer to the support services that are available.

However, this much needed collaboration is at risk, due to the impact of the COVID-19 pandemic. All.Can UK's health charity members have recorded increased demand for their support services and requests for information regarding how COVID-19 might affect people living with certain types of cancer. Furthermore, the pandemic has had a significant impact on charities due to a drop in income and available resources.

All.Can UK welcomed the £750 million of Government funding to support charities delivering frontline services and assisting vulnerable people during the COVID-19 outbreak<sup>33</sup>, but long term concerns regarding funding remain acute. To ensure the voluntary sector can continue to offer tailored and meaningful psychological and wellbeing support for people with cancer, the Government needs to provide more support for patient support charities. All additional support should be available to organisations facing financial pressures, even if they are not involved in the frontline response to COVID-19.

#### **Recommendation:**

*NHS England, in collaboration with the patient group community, should raise awareness within the oncology workforce to ensure they are aware of the entire range of psycho-social interventions offered by the third sector.*

## **Care is often 'one size fits all'**

During our evidence gathering, many charities identified concerns about the type of psychological support typically offered to people with cancer. The organisations felt that too often when emotional support is offered, it is provided in a "one size fits all" format rather than tailored to the individual.<sup>2</sup>

Patient groups have often had to fill gaps in the NHS by providing tailored support. An example is Shine Cancer Support, who were established to offer support to young adults with cancer because most support services are aimed at older people, and therefore do not take into account the specific interests and concerns of young adults. Shine offers peer support to young people through channels better suited to them, including via several social media platforms and retreats.<sup>24</sup>

Similarly, Penny Brohn UK organises tailored services at their centre in Bristol, including sessions such as an 'introduction to living well' and 'living well with the impact of cancer' during three-day retreats. They explained that:

*"Cancer impacts the whole of the person, and not just the patient, but the whole family too. It impacts their family, relationships, finances, appearance and diet. Our courses support people to feel empowered to look after themselves. It shows people that small changes can make a big impact and it doesn't have to be big, difficult steps to self-management. The course can be taken at any point in the cancer pathway".<sup>24</sup>*

Kidney Cancer UK have a helpline which provides tailored information and support to those who need it. Kidney Cancer UK recognise that people need different levels of support from basic one-off advice to ongoing support which the charity offers in the form of specialised counselling sessions. The organisation also offers grants to support people financially who might be “anxious or worrying about bills or putting food on the table”.<sup>24</sup>

The large range of support services offered by health charities highlights the range of different needs felt by patients and the importance of choice. It is clear therefore that a ‘one-size-fits-all’ approach cannot work to support the varied needs of a diverse patient population. NHS England has taken positive steps to realise this fact. In 2018, the NHS Long Term Plan committed to, where appropriate, ensuring every person diagnosed with cancer will have access to personalised care, including a needs assessment, care plan and health and wellbeing information and support. Similarly, after treatment, patients will move to a follow-up pathway that suits their needs and ensures they get rapid access to clinical support where they are worried that their cancer may have recurred.<sup>4</sup> This will be delivered in line with the NHS Comprehensive Model for Personalised Care, which supports people to manage their physical and mental health and wellbeing through practices such as shared decision making and supported self-management.<sup>34</sup>

Following the publication of the Plan, Cancer Alliances have been made responsible for working with trusts and primary care to offer these personalised care interventions to people with all cancers by 2021. All.Can is pleased to

note that good progress is being made with “over 70% of cancer care teams already offering personalised care and support planning” according to NHS England.<sup>35</sup> To ensure this figure reaches 100%, Cancer Alliances will need to work with healthcare professionals to ensure patient group materials that outline various forms of support are made available to people.

In addition, patients must also play a role in asking their healthcare professionals for the types of wellbeing support they feel they would most benefit from, whether this is attending peer support groups, contacting a health-charity-led helpline or accessing specialised counselling. There should be opportunities for patients to feedback to their healthcare professionals regarding what they have found valuable and, in turn, channels for healthcare professionals to share this information with colleagues. It will be a group effort to realise the Plan’s ambitions and ensure people with cancer can access mental health support that suits their specific needs.

#### **Recommendation:**

*The NHS should take steps to personalise services and avoid ‘one size fits all’ approaches in line with NHS England’s ambition to increase access to personalised care. NHS staff should ensure patient group materials are made available to oncology patients so that they are aware of the mental health support that they can receive.*



## Regional variation in access to care

The mental health charity, Mind, has analysed NHS data that show services across England are planning on spending differing sums of money on mental health care in 2020 and beyond.<sup>36</sup> The variation in spend on mental health services for the cancer community was also an issue raised within All.Can UK's interviews. One patient group explained *"as it stands, the NHS is not offering care evenly and nationally, so instead care needs to be offered locally"*.<sup>24</sup> Another stated that *"NHS provision is a lottery."*<sup>24</sup>

Blood Cancer UK, a cancer charity working to support people with blood cancers, consulted their policy advisory panel and heard *"15 different examples of what support they were offered and received. From absolutely nothing at all, to brilliant ongoing support. It varies depending on where they live. The difference between a patient treated in Lincolnshire to a patient treated at the Marsden could be significant"*.<sup>24</sup>

Professor Michael Sharpe, a psychiatrist and academic interviewed for this report, echoed these concerns by saying there are *"very few places that meet the full spectrum of needs well, rather there is patchy provision that tries to stretch to cover the whole range [of care within NICE's four-tier model], often doing some bits badly"*.<sup>37</sup>

NHS England has started tackling these concerns via the Long Term Plan through its targets to expand access to IAPT services for adults with common mental health problems and long-term conditions, including cancer.<sup>4</sup> While this is promising, it must translate into genuine investment in mental health services if the ambitions of the Long Term Plan and the wider cancer community are to be realised.

Challenges remain in assessing the degree to which the NHS is improving access to services or patient outcomes and experiences. There is little freely available data regarding people with comorbid cancer and mental health conditions. NHS England introduced the NHS Mental Health Dashboard (formerly the Mental Health Five Year Forward View Dashboard) to collate key data from across mental health services in order to measure the performance of the NHS in delivering the Long Term Plan for mental health.<sup>38</sup> This, however, does not contain specific data in relation to people with long-term conditions, such as cancer, and – unlike other datasets such as the Cancer Dashboard – includes no information on patient experience.<sup>39</sup>

Whilst the Government stated, in June 2020, that NHS England and NHS Improvement have no plans to include data on cancer diagnoses within the National Health Service Mental Health Dashboard<sup>40</sup>, All.Can UK is calling for this decision to be revisited. Several stakeholders have previously expressed experiencing difficulty in analysing indicators within the dashboard,<sup>39</sup> which demonstrates the need for the Dashboard to be amended to ensure it can be fully utilised. The inclusion of cancer data should be a key element to its update.

### Recommendation:

*The Government and NHS England should work to address the regional variation in access to mental health support for patients with cancer. To support this, the NHS Mental Health Dashboard should be expanded to include specific data on cancer and mental health conditions so that the NHS can have a better understanding of the level of patient need for services.*



## Case study: Maggie's<sup>41</sup>

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Excellent work is already being undertaken by the charity sector for people with cancer who require emotional and psychological support in England. This includes the work of Maggie's, an organisation which recognises that cancer creates complex and emotional issues which can affect the way people feel in their mind as well as their bodies. Maggie's offers all levels of the NICE four-tier model of psychological care for people with cancer and families within its 23 UK centres and online.

The programme of evidence-based psychological care is free, provided in a consistent and accessible format across all centres, and delivered in collaboration with NHS, social care and other third sector colleagues.

It is extremely versatile by design, easily tailored to a person's individual emotional needs, priorities and pace. For example, a person may first seek benefits advice or be attending a prostate cancer prehabilitation session (which focuses on total-body physical exercises), but with the assessment and guidance of the multidisciplinary centre team, they are helped to access whichever additional tier of psychological care they need at a time when they are most receptive to such help.

The programme addresses themes that are common to all cancers and the different

stages of a cancer experience. It includes one to one, family, and couple psychological therapies; workshops and specific courses for managing stress and anxiety, sleep and fatigue, cancer related cognitive problems, relationship problems, social isolation, returning to work, supporting children, adjusting to advanced cancer, living with dying and bereavement.

Since its beginning, Maggie's has recognised how powerful and transformative psychological care can be when offered in the safety of professionally facilitated support groups. These act as places to express emotions, share experiences and exchange coping ideas with other people in similar situations.

For people who require different levels of care, Maggie's offered level 4 psychological care by a psychologist during 10,620 instances in 2019.

# Conclusion

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There is a strong body of evidence to suggest that cancer can have a huge impact on an individual's mental health and vice versa. Despite this, both All.Can's survey and expert advice from our Working Group have shown that patients are not receiving the appropriate level of support for the psychological side of their conditions. As many cancers are increasingly being treated as long-term conditions, the health system must adapt to address the unmet psychological needs of the cancer community.

The compelling reasons why a person's mental and physical health should be given equal consideration to their physical health are clear.

Not only does this create much-needed cost-savings for the NHS but it improves patient outcomes and quality of life. As detailed in this report, there are positive initiatives now available to improve care in this area. These include the commitments made with the NHS Long Term Plan to develop personalised care plans for all cancer patients and the proposed expansion of IAPT services. These pledges are promising to see, but their implementation and impact is yet to be determined.

Furthermore, the impact COVID-19 has had, and will continue to have, on initiatives designed to support people with cancer will be felt for years to come. The Government has recognised how the pandemic is likely to increase the risk of loneliness and mental health issues, particularly for people with cancer, whose treatment was interrupted. Indeed, the Department for Health and Social Care and Public Health England are working with the NHS, social care, voluntary sector and more widely across Government to improve mental health support and provide guidance for those impacted by the pandemic. Furthermore, the Government is working with NHS England and NHS Improvement to ensure the mental health needs of those who are shielding are adequately met.<sup>42</sup> The outcomes of

this work will be important to ensure people with cancer receive the support they need, beyond the pandemic.

The aim of this report is to develop a better understanding, from patient organisations and academics, of the current barriers that prevent people with cancer from receiving the support necessary for their emotional wellbeing. The barriers identified include a lack of awareness of the mental health impact of cancer by healthcare professionals and variable uptake of screening. Furthermore, there is a limited awareness of the value of peer support with variations in signposting, meaning patients do not enjoy the full benefits of third-sector support. In addition, regional variation in care exists which sees some patients receive a 'one size fits all' approach to care, exacerbated by a lack of consistent funding and data collection through the NHS. It is clear these barriers require urgent attention to address the unmet need uncovered in our survey.

All.Can UK is calling on policy makers, Government, the NHS, industry and fellow patient organisations to work with us to take forward this report's key recommendations.

By implementing these recommendations, we can improve the lives of people living with and beyond cancer and ensure that every patient receives tailored, holistic care that supports their whole being.



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**Cancer:**  
Out of   
**Sight** **NOT**  
Out of   
**Mind**



Primary sponsor:



Secondary sponsor:

