West Midlands cancer alliance

NHS

A positive practice guide to meeting the psychosocial needs of older people with cancer

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Document Management

Revision History

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Foreword

Foreword from Dr Natasha Lord
Consultant Clinical Psychologist
Psychology Lead for Older Adults
Midlands Partnership University NHS Foundation Trust
Chair of DCP Faculty of the Psychology of Older People | BPS

As Chair of the Faculty of Psychology of Older People (FPOP), part of the Division of Clinical Psychology (DCP), British Psychological Society (BPS), I am really pleased to see the development of this guidance, and its impact will undoubtedly be significant. For many years, the needs of older people have gone under-recognised (Centre for Mental Health, 2024), with calls for change often citing parity, which as this document clearly demonstrates does not mean "receiving the same". We welcome guidance that puts older people living with and beyond cancer at the forefront; offering practical, tangible ways that services can implement change to increase support. The authors rightly highlight age as a protected characteristic that is often overlooked as a health inequality, yet older people are the fastest growing cohort. We agree with the authors that the guidance will positively impact beyond improvements to psychosocial care experiences and will support with alleviating wider system pressures faced by staff and services.

The guidance outlined how the needs of older adults living with and beyond cancer are not widely understood, both within cancer services, and other health and social care services. It has succinctly and eloquently pulled together key impact areas for services to consider in a clear, easy read format. It makes link to the evidence and suggests resources for the existing workforce. The strong emphasis on increasing the voices of older people, their families, friends and carers through Champions, feedback, and research are warmly welcomed.

This guidance further develops both a competency framework for healthcare professionals and a call to work more closely across mental health and physical health services. The report recognises the complexities of aging, with increased likelihood of multi-morbidities and the potential negative impact on people, their carers and families when services are not interacting. The authors succinctly demonstrate the importance of paying attention to the physical-mental health interface and working together, through a mixture of research, published guidance, and lived experienced feedback. They recognise and call for more research and evaluation to be completed in this area, and the guidance provides a frame for holistic, joined-up care.

As a faculty dedicated to raising the profile of older people's needs, we strongly recommend the guidance for all practitioners working in settings where they meet older people living with or living beyond cancer. By increasing access to

psychosocial support and ensuring better cancer related health literacy for older people, carers, families and friends it will enable better outcomes for all.

Dr Natasha Lord

Foreword from Dr Lydia Fresco MBBS, FRCR,
Consultant Clinical Oncologist
Clinical Director, West Midlands Cancer Alliance

As Clinical Director for West Midlands Cancer Alliance, I am delighted to bring you this Guide to Meeting the Psychological Needs of Older People with Cancer.

This evidence-based document has been developed by Dr Ayşe Gürpınar in partnership with the West Midlands Cancer Alliance Psychosocial Expert Advisory Group and is informed by the best available published evidence along with expertise from psychosocial and other healthcare professionals and people with lived experience of cancer.

In West Midlands Cancer Alliance, we advocate for parity of esteem for mental health and physical health. The right psychological support, at the right time and in the right place should be seen as an integral part of the cancer pathway to empower everyone with cancer to enhance their own mental health and well-being, thereby supporting them to live life as fully as they can. In addition to quality of life factors, it is increasingly recognised (and I have observed this in my years of clinical practice) that people are less vulnerable to the side effects of cancer treatment if they are as healthy as possible right from the start - not only physically, but also psychologically. People with cancer who have poor mental health are known to be more vulnerable to the adverse effects of cancer treatments, have poorer adherence to treatment regimens and have poorer long-term health prospects, irrespective of cancer type and stage of disease1.

Furthermore, cancer and aging are deeply interconnected, with aging being one of the most significant risk factors for developing cancer. In this guidance, Dr Gürpınar outlines some of the specific emotional and mental health challenges faced by older adults with cancer that significantly affect their overall well-being and treatment outcomes. The document outlines potential solutions for individuals and services and includes consideration of intersectionality with a number of other factors such as increased likelihood of other long-term conditions and frailty.

In short, addressing the emotional needs of older adults with cancer is not only compassionate, it is a vital component of holistic, personalised cancer care that improves both survival and quality of life. Psychological support is everyone's business, not just the responsibility of specialist psychology professionals. Whether

you are a health or social care professional, a service commissioner, a manager, a patient advocate or are reading this guidance in another capacity, you will find strategies and recommendations to help shape services to better meet the psychological support needs of older adults with cancer thereby improving outcomes and quality of life.

[1] Source: Macmillan Cancer Support (2019) Principles and guidance for prehabilitation within the management and support of people with cancer. https://www.macmillan.org.uk/healthcare-professionals/news-and-resources/guides/principles-and-guidance-for-prehabilitation

Key Terms

Co-production: A collaborative approach where professionals and patients work together from start to finish to design, develop and evaluate services.

Health inequalities: Preventable differences in how groups of people experience health care.

Lived experience: To have personal experience of something, such as a health condition, or of using a particular health service, whether as a patient or a family member, carer or friend of a patient.

Older people: Defined in this context as those aged 65 years or older at the time of a cancer diagnosis.

Protected characteristics: Attributes protected from discrimination as outlined by the Equality Act 2010.

Psycho-oncology: An interdisciplinary field of oncological care that provides psychosocial interventions to support those living with and beyond cancer.

Psychological therapies/Talking therapies: A range of evidence-based therapies delivered by appropriately trained and accredited professionals to support people with mild to moderate mental health difficulties, like depression, anxiety, stress, and worry.

Safeguarding: Protecting a person's health, well-being, and human rights.

Signposting: Directing a person to key information and services.

Trauma-informed: A way of working that realises the impact and recognises the signs of trauma to be able to respond in a sensitive and person-centred way.

West Midlands Cancer Alliance: A partnership organisation funded by NHS England to work collaboratively with the local NHS services, networks and integrated care boards, to deliver the national Cancer Taskforce strategy.

Executive summary

Objectives

This guidance aims to reduce psychological distress in older people affected by cancer and their families and carers, by improving the accessibility and experience of psychosocial care. Drawing on national cancer patient data, clinical research, and lived experience, this guidance details how older people interact with and experience the cancer pathway. Ideally, this positive practice guide will elucidate the key challenges faced by older people affected by cancer and will equip healthcare staff and services to adapt their practice to better meet the needs of older people and their families and carers.

Methodology

For a brief overview of the guidance methodology, including the number of stakeholders who supported with the development of this document, please see Appendix 6. A thorough literature review of the existing policy and research was conducted, and findings were synthesised to inform the development of qualitative surveys which were sent out to various stakeholders to enable coproduction. Stakeholders included older people with lived experience of cancer and service user advocates from the West Midlands, and both regional and national healthcare professionals across several disciplines: clinical health psychology and psycho-oncology services; older adult specialist mental health services; primary care services; oncology and palliative cancer services and local authority providers working with people diagnosed with cancer, their families and carers.

Several small working groups were facilitated to further explore the issues identified by stakeholders and to discuss and plan the content, structure, and evaluation of the guidance. Key discussion and consensus points were drawn from the feedback data, and a thematic analysis was conducted. In consultation with stakeholders, key themes were identified and developed into evidence-based recommendations for how healthcare professionals can consider and better address the needs of older people affected by cancer.

The guidance document underwent several rounds of review, where stakeholders were given the opportunity to provide further feedback. The final document was reviewed and ratified by the West Midlands Cancer Alliance Board and Psychosocial Expert Advisory Group.

Key findings and section overviews

The development of this guidance was a recommendation of the West Midlands Cancer Alliance (WMCA) Psychosocial Mapping Report (Gürpınar et al., 2023) and as such has a regional focus, although it is recognised that many aspects of this

positive practice guide will be relevant to the current cohort of older people across England.

The feedback we received, along with the existing policy and research, suggests that the psychosocial care experiences of older people affected by cancer and their families and carers can be positively impacted by focusing on the following areas:

- reducing structural barriers to being able to access psychosocial support
- Increasing health literacy and reducing digital exclusion
- improving communication between and within healthcare systems
- improving communication with people affected by cancer about care needs and planning for the future
- recognising the specific needs of older people in relation to sexual health and intimacy, managing caregiving responsibilities alongside cancer, challenges associated with poor mental health, dementia and cognitive impairment, poor physical health and frailty, safeguarding, risk and suicide prevention, and case formulation.
- working in partnership with families and carers.

The key findings have been expanded upon in four sections:

Section 1: Increasing equitable access to psychosocial support

Section 2: Understanding the psychosocial needs of older people

Section 3: Working in partnership with families and carers

Section 4: Training, education, and support for staff

Section 1 focuses on increasing equitable access to psychosocial support services across the West Midlands for older people, their families and carers. This section makes recommendations to identify, remove or reduce barriers to access that might prevent some older people from being able to benefit from psychosocial support. This section is relevant to all healthcare professionals and is useful in highlighting the challenges that older people may face when attempting to engage with services.

Section 2 looks at how services can understand and accommodate the diverse and varied psychosocial needs of older people living with and beyond cancer. This section includes 10 sub-sections, each dedicated to key themes that impact the experience of care and psychosocial outcomes as identified by literature, research, and the stories of older people living with and beyond cancer, their families and carers (see Figure 4). This section is relevant to all healthcare professionals working with people with cancer. However, the final subsection ‘Formulation: Therapeutic considerations and case conceptualisation’, is most likely to be relevant to healthcare professionals providing support at the specialist level.

Section 3 focuses on working in partnership with families and carers across the West Midlands and makes recommendations to increase the identification and prevention

of psychological distress in family members and carers of older people with cancer. This section is likely to be relevant to healthcare professionals providing support at all three levels.

Section 4 focuses on training, education, and support for the workforce and makes recommendations to facilitate the delivery of compassionate care for older people with cancer to operationalise the recommendations in the preceding sections. It is most relevant for all commissioners of health education; service leads and managers.

Outcome and evaluation

In response to the key findings and informed by the evidence base, 100 best practice recommendations have been made across each of the four sections of this guidance and have been dichotomised into older adult specific and all-age recommendations (see Appendix 1 for a complete list). The recommendations informed the development of two self-assessment audit tool templates to help healthcare professionals evaluate their practice and to encourage service users to think about the care they have received in the cancer pathway (see Appendix 5). Standards have been created in line with the competencies highlighted throughout this guidance, with hopes of improving psychosocial care experiences and empowering older people affected by cancer and their families and carers to work in partnership with professionals involved in their care.

Future directions

An implementation resources toolkit has been developed to guide regional integrated care boards (ICBs) looking to begin service improvement projects relevant to local population needs in response to this guidance. The toolkit can be found on the West Midlands Cancer Alliance Psychosocial Webpage. (insert link once approved by Board)

Introduction

Getting health care right for older people helps to ensure we get it right for everyone (British Geriatrics Society, 2021).

The development of this guidance

In partnership with professionals and experts by experience in the field of cancer care and older adult mental health, this guidance has been developed from a review of clinical and research literature and existing policy and practice guidance (see bibliography for full list on page 59) and is a shared agreement of what good psychologically-informed cancer care for older people should be. A thematic map is provided in Appendix 3, which gives an overview of the underpinning principles of each of the themes explored in this guidance.

The context of this guidance

This guidance was developed in response to the findings of the West Midlands Cancer Alliance Mapping of Psychosocial Support Services (Gürpınar et al., 2023), which highlighted the need to develop best practice guidelines for cancer patients with protected characteristics, to improve their experience of psychosocial care.

The mapping report made recommendations for implementation that are being progressed under the psychosocial care agenda within the six ICBs of the West Midlands, supported by West Midlands Cancer Alliance's investment in a systems-level approach, which helped set up dedicated ICB cancer board task and finish groups. Several of those recommendations are within the scope of this guidance, including increasing access to the provision of psychosocial support in the West Midlands, tackling health inequalities relating to psychosocial care, identifying and addressing region-specific shortfalls in care quality to increase patient satisfaction levels, and increasing the psychological support provisions available to the cancer workforce to protect and improve staff wellbeing. Further recommendations on gaps in commissioning of the support workforce, service delivery and capacity/prioritisation criteria are outside the scope of this guidance.

Scope, key definitions and guiding principles

This guidance will focus on the protected characteristic of age (Equality Act, 2010) and aims to improve the psychosocial experience of cancer care for older people by supporting services in becoming more inclusive as the population of the UK becomes more diverse. Ideally, this guidance will positively impact beyond improvements to psychosocial care experiences and will support with alleviating wider system pressures faced by staff and services. In this guidance, older people are defined as people aged 65 years or older. We use the term 'family and carers' to refer to anyone who provides support of any nature to the person living with or beyond cancer. In doing so we acknowledge that for some older people this may be a chosen family of friends or neighbours in addition to or instead of one's biological family.

This guidance is relevant to all cancer, haematology, neuro-oncology and palliative cancer care services but does not make specific recommendations for specialist neuropsychological practitioners.

This guidance adopts the British Geriatric Society definition of frailty as “a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves” (BGS, 2014). This guidance recognises that frailty is not an inevitable consequence of ageing; around 10 per cent of people aged over 65 years have frailty, rising to between a quarter and a half of those aged over 85.

This guidance recommends the adoption of a trauma-informed approach (Cavell & Curtis, 2024) to psychosocial support for older people affected by cancer. The seven principles of trauma-informed practice underpin the recommendations within all the sections of this guidance, and these are: safety, trust, choice, collaboration, empowerment, cultural consideration and connection (Cavell & Curtis, 2024). The West Midlands Trauma Informed Workforce Learning and Development Framework highlights that central to this ethos are the person-centred values of empathy, kindness, and humility.

Providing trauma-informed care across the cancer pathway is important because many older people will have experienced adversity in life prior to a diagnosis of cancer. Trauma-informed practice is an approach to health and care interventions which is grounded in the understanding that trauma exposure can impact an individual’s neurological, biological, psychological and social development (Office for Health Improvement and Disparities, 2022) and that a diagnosis of and/or treatment for cancer compound the impact of previous trauma (Delahanty et al., 2015).

In 2020, an integrated model of care was developed by the London Transforming Cancer Services Team which featured three levels of support: universal, enhanced, and specialist. Each level maps on to NICE (2004) four-level model of psychological support and assessment (e.g., universal maps on to NICE level 1, enhanced maps on to NICE level 2, and specialist maps on to NICE level 3 & 4). For an in-depth overview of both models, see Appendix 2. The scope of this guidance is to provide recommendations that are actionable across all levels of psychosocial care and support.

NHS Talking Therapies for Anxiety and Depression (NHS TTAD) are regional services that offer psychological interventions either as standalone or in the context of co-morbid long-term physical health conditions (LTC), including cancer (BABCP, 2024). NHS TTAD services do not have an upper age limit; however, compared to their working age counterparts, older people have consistently received less referrals to the programme since its inception, despite being just as likely to respond well to treatment (BABCP, 2024). The NHS Talking Therapies Positive Practice Guide for Older People (BABCP, 2024) was developed to reduce this referral gap and increase the number of older people benefitting from NHS TTAD services.

How to use this guidance

Integrated care boards (ICBs) and service leads are encouraged to use this guidance to identify and prioritise key recommendations within their local service areas, and to ensure delivery through their ICB Cancer Programme Psychosocial Task and Finish Group Terms of Reference, remit, and process.

Each section makes recommendations for healthcare professionals working at the universal, enhanced and specialist support levels of the integrated pathway for cancer support, in line with the recommendations of the West Midlands Cancer Alliance Mapping of Psychosocial Support Services (Gürpınar et al., 2023). A summary of the key findings of the mapping is presented on page 12.

The **increasing equitable access** section (page 21) focuses on reducing barriers to psychologically informed care across the cancer pathway and is likely to be relevant for all healthcare professionals and service leads working with older people affected by cancer.

The **understanding psychosocial needs** section (page 24) highlights the diverse psychosocial needs of older people and makes recommendations for clinical adaptions to practice and is likely to be relevant for staff working across all levels of support. This section has been further subdivided into 10 themes identified in partnership with stakeholders to include:

- Lifespan perspectives on cancer (page 25)
- Increasing health literacy and reducing digital exclusion (page 27)
- Communication (page 33)
- Conversations about care needs, wishes and managing unexpected situations (page 35)
- Sexual health and intimacy (page 37)
- Understanding the needs of older caregivers with cancer (page 39)
- Mental health, dementia and cognitive impairment (page 41)
- Physical health and frailty (page 45)
- Safeguarding, risk and suicide prevention (page 47)
- Formulation: Therapeutic considerations and case conceptualisation (page 50)

The **working in partnership with families and carers** section (page 51) looks at how staff can deliver psychological support that is inclusive of families and caregivers of older people living with and beyond cancer.

The **training, education, and support for staff** section (page 55) highlights recommendations to empower healthcare staff working with older people affected by cancer and is relevant for staff working across all levels of support, in addition to service leads, managers and education leads.

Summary of key findings from the West Midlands Mapping of Psychosocial Support for People Affected by Cancer:

The provision of psychosocial support in the six integrated care services of the West Midlands varies significantly and the findings highlight fewer staff than needed based on local population and cancer diagnostic data (Gürpınar et al., 2023). The report found that many psychosocial services do not offer direct or indirect therapeutic input in the home or in inpatient or residential or nursing home settings, which will disproportionately impact on the accessibility of psychosocial support for older people.

Carer support in the West Midlands is limited and most cancer services refer to third sector voluntary and community social enterprise (VCSE) organisations such as Macmillan, Penny Brohn and Maggie's Centres. The majority of NHS Trusts providing psychosocial support to people with cancer do not accept referrals for carers or family of people at the specialist level or have other restrictions around access to support. Talking Therapies for Anxiety and Depression (formally known as IAPT) do not collect data on carer status.

Healthcare professionals working at the enhanced level across the ICBs reported barriers to referring people with cancer for psychosocial support, which included an awareness of the pressures on their local psychosocial team and low (or in some areas no) baseline resource to refer onto at the specialist level if psychosocial needs were identified. Healthcare professionals at the enhanced level also acknowledged not having the training, time or emotional capacity to conduct in-depth holistic needs assessments. There is variability across the West Midlands in terms of which Trusts and which professional disciplines are able to access 'level two psychosocial interventions training' (at the enhanced level) from a level three or four (specialist level) practitioner within the ICB. Supervision for cancer professionals working at the enhanced level from a practitioner at the specialist level was variable, with no access to clinical supervision or training at some Trusts due to limited or no resource, capacity issues and/or commissioning arrangements.

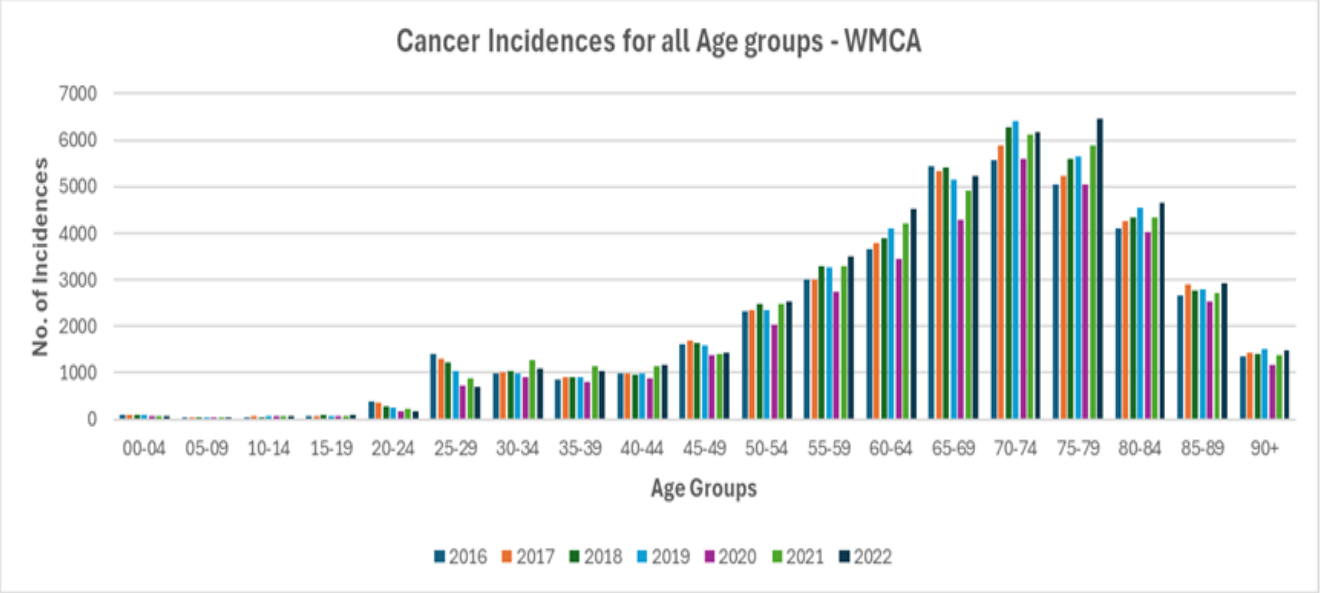
Investment in the cancer workforce through providing access to training and supervision was a key recommendation of the mapping report and this is being taken forward within the implementation phase of the Cancer Alliance psychosocial programme 2023-2025.

Why do we need to improve the psychosocial experience of cancer care for older people in the West Midlands?

Currently, the number of people living with cancer in the UK is estimated to be more than 3 million, with around 390,000 people receiving diagnoses each year (Macmillan Cancer Support, 2024a). In 2021, people aged 65 and over accounted for 60% of cancer diagnoses recorded (NHS England, 2023).

Figure 1

The number of older people diagnosed with cancer in the West Midlands between 2016-2022.



Source: https://cancerstats.ndrs.nhs.uk/COSD/Level3

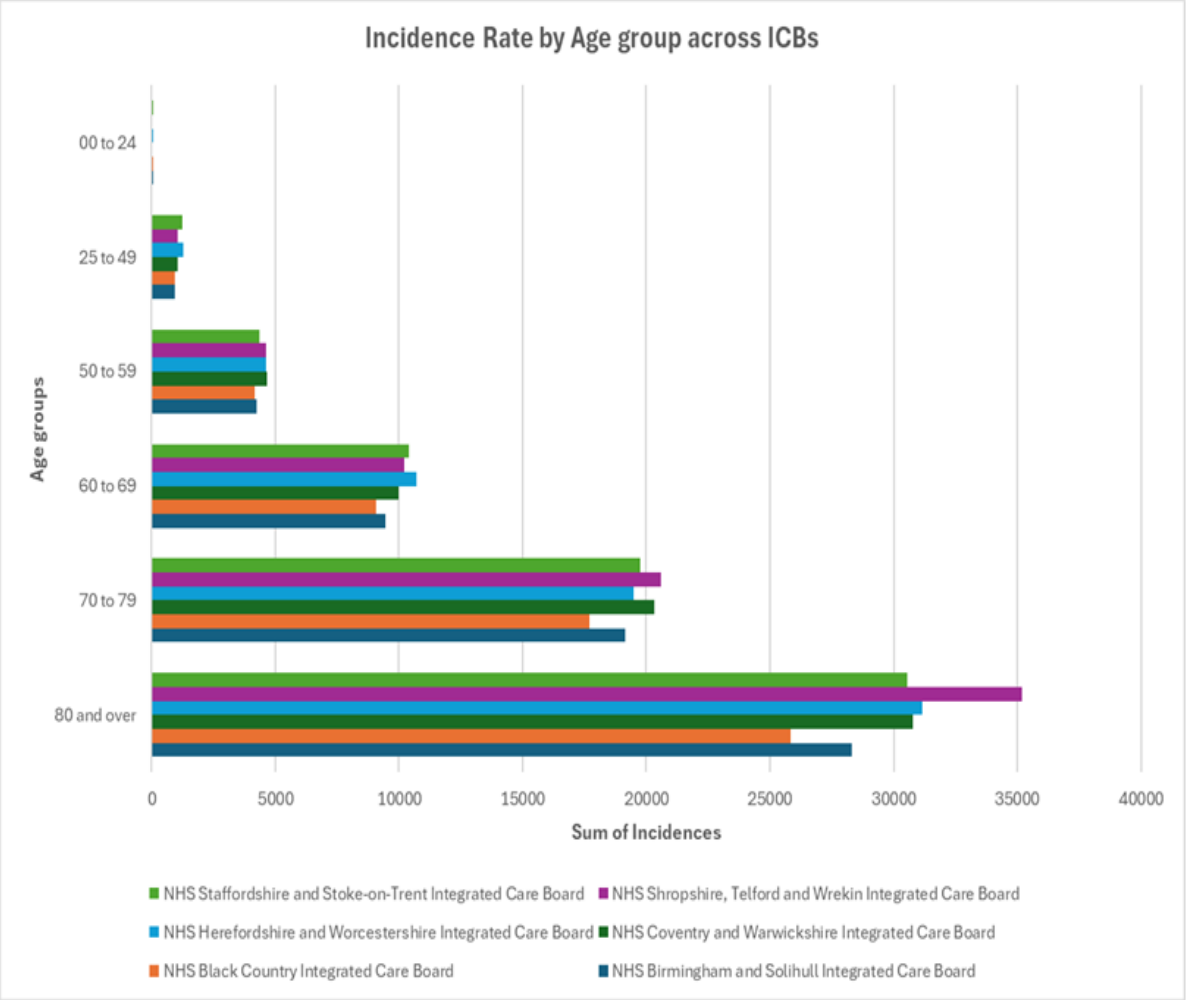
With earlier screening and diagnosis, the outlook for many people with cancer has improved, with people living longer with and beyond cancer than before (Macmillan, 2024a). Moreover, the general UK population is steadily increasing, in part due to longer life expectancies because of improved healthcare (Office for National Statistics [ONS], 2024). Whilst positive, these outcomes increase the likelihood that more older people will be affected by cancer in the coming years.

The West Midlands is characterised by densely populated urban areas such as Birmingham, Sandwell, Wolverhampton, Coventry and Stoke, and many rural areas, particularly within the counties of Herefordshire, Shropshire, Worcestershire and Staffordshire. A recent comprehensive report on our ageing population by the Centre for Ageing Better (2023) highlighted that we need to prepare for an increasingly diverse older population with cancer. The report emphasised that people are living for longer, with the population aged 80 years and over experiencing the fastest growth. The report indicated that deprivation in the West Midlands is higher than the national average. Rural communities have higher proportions of older people, and

the rates are increasing. The proportion of younger people is expected to decrease. Older groups are becoming more ethnically diverse.

Figure 2

2022 incidence rates across ICBs by age group.



Source: https://nhsd-ndrs.shinyapps.io/prevalence/

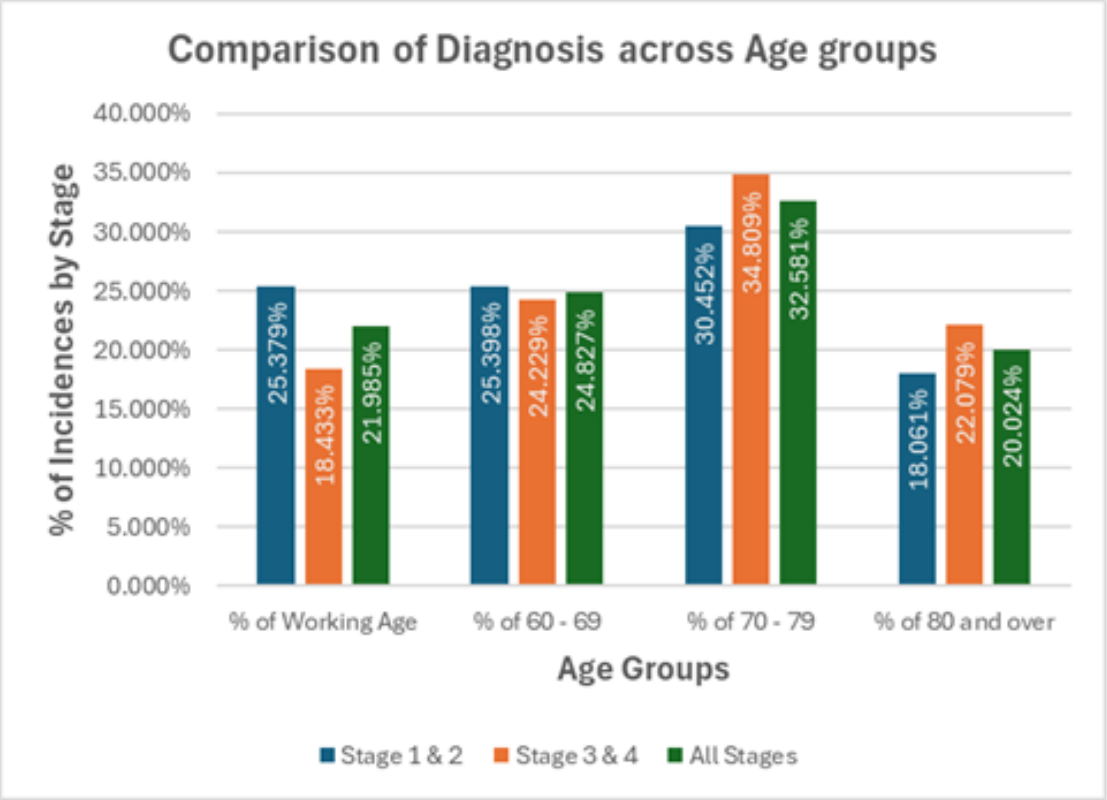
The report also found that lifestyles are changing, with more people living alone and remaining unmarried; approximately 4.5 million older people are estimated to live alone by 2043. Moreover, people are more likely to be unpaid carers if they are: aged 50 years and over, women, disabled, from ethnic minority backgrounds, and living in deprived areas. The report suggested several implications relevant to older people including the potential for more people living with age-related health decline and disability, more older people requiring long-term condition management, alongside an increase in older caregivers living in deprivation with their own long term health conditions to manage. This means that existing health inequalities are likely to worsen over time, with less social support available (both community and intra-familial) for older people and underserved communities likely to become increasingly “hard to reach”.

It is crucial to identify and better understand the needs of older people with cancer as we move towards caring for an increasingly diverse ageing population. Older people with cancer are at higher risk of experiencing discrimination within healthcare services and frequently report less favourable care experiences than their younger counterparts (Reeves et al., 2024).

As older people have been routinely systematically excluded from cancer research and clinical trials, less is known about how cancer can be prevented and treated in older adults (Bumanlag et al., 2022; Hurria, 2007). Older people are more likely to receive a later stage cancer diagnosis (see Figure 3 below), be offered less intensive treatment, and experience worse clinical outcomes. These disparities are compounded further by clinical practice based upon unhelpful stereotypes of old age, where cancer symptoms are often reduced to frailty and other 'expected' age-related changes (Haase et al., 2023).

Figure 3

Cancer stage at diagnosis for older people compared with working age people.



Source: https://nhsd-ndrs.shinyapps.io/incidence_and_mortality/

Older people face a unique set of challenges in coping with emotional distress during their cancer journeys. For instance, older people may hold stigmatising attitudes and beliefs about mental health, which could impact their likelihood to seek support from services. In addition, older people are less likely to have close support networks that might advocate for their psychological support needs and help them to express their

needs to healthcare professionals. Healthcare professionals are unlikely to have received training in the psychosocial needs of older people and may not recognise the ways in which the current cohort of older people in distress may present. These factors may explain why older people with cancer are less likely to be referred to psychosocial support services than their younger counterparts (Estape, 2018).

Research shows people with lower incomes and those experiencing socioeconomic disadvantage drop out of chemotherapy and radiotherapy because of the financial impact of having to attend daily or weekly treatments (Shand et al., 2024), which is consistent with local data from an ongoing review of treatment attrition in Birmingham and Sandwell. Older people in poverty are less likely to be able to travel to outpatient appointments or groups for psychosocial support, which disproportionately affect older people with cancer living greater distances from community health resources.

Health inequities are exacerbated when older people share intersecting marginalised identities. For instance, people from minority ethnic communities report longer diagnostic intervals, less favourable care experiences, more access barriers, and lower survival rates than their White counterparts (Race Equality Foundation, 2024). There is also evidence of sex disparities in cancer care, with chemotherapy being offered in similar proportions across sexes despite women experiencing more adverse side effects (Kim et al., 2018). The likelihood of receiving intensive treatment decreases significantly in older age populations compared to younger people (Public Health England, 2020).

The recommendations made within this guidance are guided by the findings of intersectionality research that explores the impact systemic power imbalances have on producing and perpetuating health inequalities (for a more in-depth discussion, see Hankivsky et al., 2017 and bibliography). The following section provides an overview of the key differences in experiences of the cancer pathway, by people who share protected characteristics that are disproportionately affected by health inequalities.

Understanding the intersecting identities of older people

Older people are not a homogenous group. Identity can encompass many aspects of how an older person sees themselves and can include sexual identities, gender identities, cultural identities and spiritual identities.

It is important to develop an awareness of how age may overlap with personal characteristics such as sex, gender, sexuality, race, ethnicity, education opportunities, health literacy and socioeconomic status to impact on the experience of cancer and in turn, the experience of curative cancer treatment, palliative and end of life cancer care. Moreover, considering intersectionality is essential to ensuring that the psychosocial support and guidance offered to older people is personalised.

Age and LGBTQ+ identities

Some of the key psychosocial issues experienced by older LGBTQ+ people with cancer include:

- Older lesbian women and gay men perceived that their sexual identities reduced their social and familial support and found cancer services inadequate in bridging this gap (Westwood, 2017).
- Older LGBT people reported anxiety around accessing palliative cancer care and end-of-life care for fear of discrimination, privacy concerns, and having to bear the emotional toll of disclosure (Almack, 2017).
- Older LGBT people were concerned their wishes may not be respected (e.g., choosing a next of kin that was not a relative, partners being involved in funeral planning (Almack, 2017).
- Older transgender people expressed a lack of needs-specific care being offered (e.g., continuing hormone therapy throughout end-of-life care, personal care considerations; Almack, 2017).

Age and sex

Some of the sex differences experienced by older people with cancer include:

- Women experience significantly longer intervals between symptoms and diagnosis than men, with intervals increasing with age, highlighting the greater risk faced by older women (Din et al., 2015).
- Older women are less likely to be offered intensive treatment (Neal et al., 2022).
- Men accessing chaplaincy in the later stage of a palliative illness were less likely to initiate conversations about death and dying than women (Skulason et al., 2014).

Age and race and ethnicity

Although older people from minority ethnic backgrounds are significantly and disproportionately impacted by health inequalities, deprivation and social exclusion (Gervais, 2015), they are rarely included in research and frequently overlooked in policy (Macmillan Cancer Support, 2021). The data available suggests health inequalities worsen as people from ethnic minority backgrounds age (NHS England, 2020a). In both women and men, several ethnic minority groups report worse health than their White British counterparts, with gaps widening as age increases. For instance, the rates of poor health for white British women in their 80s are comparable to, or lower than, the rates of poor health for some ethnic minority women in their 50s (Stopforth et al., 2023).

Research suggests that these health disparities stem from several factors including repeated exposure to racism and socioeconomic disadvantage across the lifespan (Stopforth et al., 2023). As people from ethnic minority backgrounds age, exposure to these factors is prolonged and accumulates in a higher likelihood of experiencing poor mental and physical health. Partnered with the systemic and structural exclusion experienced by older people from ethnic minority backgrounds, their vulnerability becomes even greater.

Some of the key issues are explored in the Macmillan report No One Overlooked: Experiences of BME people affected by cancer (Gervais, 2015) and include:

- Language barriers, perceptions of age-related discrimination, healthcare professionals making assumptions about needs, and cultural barriers to treatment (NHS England, 2020a).

Age and disability

Some of the key psychosocial issues experienced by older people with cancer and disabilities include:

- Balancing the harms and benefits of cancer treatment, being an active participant in care decisions, maintaining independence, worries related to caregiver burden, social isolation, poor coordination of care and inter-system communication, and balancing practical implications of multiple hospital visits (Seghers et al., 2023).
- Older people with learning disabilities are more likely to have unmet social needs that impact communication, physical activity levels, and opportunities for connection (NICE, 2018a).
- As of 2018, 1 in 34 children and young people hold an autism diagnosis in England, compared to 1 in 6000 people over the age of 70 (O'Nions et al., 2023). Moreover, the likelihood of receiving a diagnosis for attention-deficit hyperactivity disorder reduces significantly with age (Dobrosavljevic et al., 2020). Therefore, it is likely that many older people are unaware of their neurodivergence and as a consequence may be less inclined to advocate for their support needs. The psychosocial impacts of neurodivergence typically include difficulties with social communication, memory, attention, executive functioning, emotional regulation, and psychological flexibility (Janicki et al., 2022).

Age and religion and culture

Some of the key psychosocial issues experienced by older people with specific religious and cultural needs:

- For some older people, their own beliefs might influence the acceptance of palliative and end of life care support as it may be viewed as disrespectful or incongruent with beliefs about a higher power (NHS England, 2020a).
- Healthcare professionals may hold assumptions that perpetuate lower referrals to support services, such as family are willing and able to take on the role of caregivers (Calanzani et al., 2013).
- Services that are not designed to offer sex-specific or religion-specific support or chaplaincy (CQC, 2016).

Age and deprivation

Some of the key issues experienced by older people living in the most deprived areas compared to those in the most least deprived include:

- Higher likelihood of having to drop out of chemotherapy and radiotherapy because of the financial impact of having to attend daily or weekly treatments (Shand et al., 2024)
- Reduced availability of local healthcare resources and less likely to have access to a smartphone, computer or broadband in the home and be at risk of digital deprivation and exclusion (Centre for Ageing Better, 2023).

Age and imprisonment

The prison population in England and Wales is ageing, with the number of older people (aged 50+) increasing by 67% between 2010 and 2022, and set to increase to 14, 800 by July 2025 (Ministry of Justice, 2021). Prisoners face worse health inequalities than the general population, perpetuated by systemic barriers to accessing hospital care leading to a reduced likelihood of undergoing curative cancer treatment and an increased risk of death (Lüchtenborg et al., 2024). Between 2016 to 2020, 190 older prisoners were admitted to hospital, of which 40% had a cancer diagnosis, and 100 older prisoners received palliative care, of which 30% had a cancer diagnosis (Davies et al., 2023). Older prisoners with cancer are admitted to hospital at significantly lower rates than the general population, likely due to poorer screening and detection, and thus lower levels of treatment (Davies et al., 2023). Therefore, it is important to consider the complex challenges faced by older prisoners with cancer when delivering cancer care, including:

- Increased risk of co-morbidities, frailty, dementia and Alzheimer's disease.
- Reduced social support (e.g., family and friends not allowed to attend appointments)
- Stigma and shame (e.g., use of restraints in hospital settings)
- Fear of violence and bullying from other prisoners due to side effects of cancer and/or cancer treatment (e.g., hair loss, incontinence, physical weakness)

- Poor integrated care pathways between prisons and NHS cancer services impacting psychosocial care experiences

The following sections of the guidance offer a summary of the key messages and recommendations for services to be more responsive to the many and varied needs of older people within the West Midlands.

SECTION 1. Increasing equitable access to psychosocial support

This section looks at how services can increase the accessibility of cancer and palliative cancer care psychosocial support services across the West Midlands for older people, their families, and carers.

This section makes recommendations to remove the structural barriers to access that might prevent some older people from taking up support offered.

The potential training and support needs of the workforce in developing skills such as identifying psychological distress in older people, adaptations that might need to be made to be able to better assess distress in older people and make onward referrals to specialist services are addressed in the sections Psychosocial Needs of Older People with Cancer (page 24) and Training, Education and Support for the Cancer Workforce (page 55).

Older adults are consistently underrepresented in psychological services at the specialist level compared to working age adults, despite the evidence strongly suggesting older people are likely to achieve the same, if not better, outcomes from therapy (Saunders et al., 2021).

There are several barriers to being able to access psychological support as an older person including:

- Limited resources within services.
- Older people may minimise their experience of distress when speaking with healthcare professionals due to not wanting to take up time (Lawrence et al., 2006).
- Competing organisational strategies such as green, digital and cost reduction initiatives being at odds with inclusivity.

Several access barriers arise for older people where psychological support services use an opt-in model of referral and/or wait list management (Prosser et al., 2024); that is a system requiring people to make contact after a referral has been made, in order to confirm a desire to engage, to be offered or to commit to an appointment before it is offered to another person on a waiting list. If unable to receive or respond to text messages, or processes appear impersonal or confusing, older people are less likely to opt-in and are at greater risk of being discharged without accessing an assessment or intervention.

Older people are more likely to be excluded from referrals to NHS TTAD services, particularly those with physical disabilities, cognitive impairment, learning disability or those belonging to minority ethnic groups (BABCP, 2024). Research suggests that referral gaps for older people may be attributable to limited knowledge of what NHS TTAD services offer, combined with commonly held misconceptions amongst healthcare practitioners that services and talking therapies are inaccessible,

inappropriate, inefficient and ineffective for older people (Collins & Corna, 2018). Additionally, it is likely that lower levels of referrals are compounded by older people's tendencies to take on passive roles as recipients of healthcare (Doekhie et al., 2020).

People living in residential or nursing homes are even less likely to be able to access psychosocial support although they may have the same or greater needs than older people living in the community (Craig et al., 2023). Their experience depends heavily on the care environment, the resources available, and the support from family and healthcare professionals knowledgeable about older people's mental health. Research has pointed to difficulties in accessing pain management, symptom control, and nutrition support, while psychological needs include lack of social support, loneliness and lower emotional well-being overall than people living in the community.

Older people who live in rural areas of the West Midlands are more likely to be disadvantaged by factors such as limited access to local resources, and the need to travel is likely to contribute to anxiety (and concern about being a burden to family or carers; Butow et al., 2012).

For some older people, the decision to delay or forgo treatment or attend treatment less infrequently than is optimal may be based on financial distress and research suggests that this aspect of quality of life is not always considered by healthcare professionals in the planning of cancer treatment or psychological support (Arastu et al., 2020). This is especially relevant in relation to travel to the regional cancer centres (including Royal Wolverhampton Trust, University Hospitals Coventry and Warwickshire, University Hospitals Birmingham) for treatments such as radiotherapy.

Recommendations

1. Services should avoid using "opt-in" models which exclude older people with low literacy, English as a second language, cognitive difficulties and digital deprivation.
2. Services should work in partnership with Equality Leads, Patient Experience teams, local communities and organisations representing service users who are under-represented in support services to find suitable models of service that do not contribute to the inequalities above.
3. Services should collect race, sex, disability (including LD/MH), sexual identity and gender diversity characteristics within the cancer registry to improve understanding of the needs of the community.
4. Seek to promote accessible services using simple language in letters and on signs, clear signage and accessible routes into clinical areas.
5. Send photographs of the entrance to the building and any complex internal routes with first appointment letters.
6. Consider parking, affordability of travel/public transport, mobility and sensory friendly environments.

7. Consider using audit tools to adapt areas into dementia-friendly environments to reduce the potential for additional anxiety and confusion caused by attending hospital or outpatient clinics. For example, Environments for Ageing and Dementia Design Assessment Tool (Dementia Services Development Centre, 2022) and Dementia Friendly Environment Checklist (Alzheimer's Society, 2024). These make suggestions of a practical nature, such as ensuring regular resting places along corridors in treatment centres or outpatient clinicals areas.
8. Healthcare professionals should consider how an older person will get to appointments if they are not going to be seen at home and be aware of the financial impact of travel; signposting to information and support in relation to financial distress such as Citizens Advice Bureau, Age UK and Macmillan.
9. Be flexible and offer appointments at an appropriate time of day, which may mean excluding early morning or late afternoon appointments to support older people with chronic pain, cognitive impairment and/or other disabilities to attend at their optimal time to benefit most from therapeutic interventions (for instance some people with dementia may experience a worsening of symptoms late afternoon).
10. Avoid appointments at peak travel hours so that people can benefit from discounted or free public transport such as senior railcards and older people's bus passes.
11. When considering a referral for psychosocial support at the enhanced or specialist level, be aware that older people may have different understandings of what psychological therapy involves. It is important to offer opportunities to ask questions and signpost to resources for more information.
12. Local psychosocial service leaflets and websites should be made accessible to older people and be offered in print as well as digitally.
13. Older people may talk about their feelings of anxiety and depression differently and use different language to working age adults. They may speak in terms of physical symptoms such as "nerves", bodily ailments or withdrawal from activities or social relationships, which could indicate anxiety, low motivation or hopelessness.

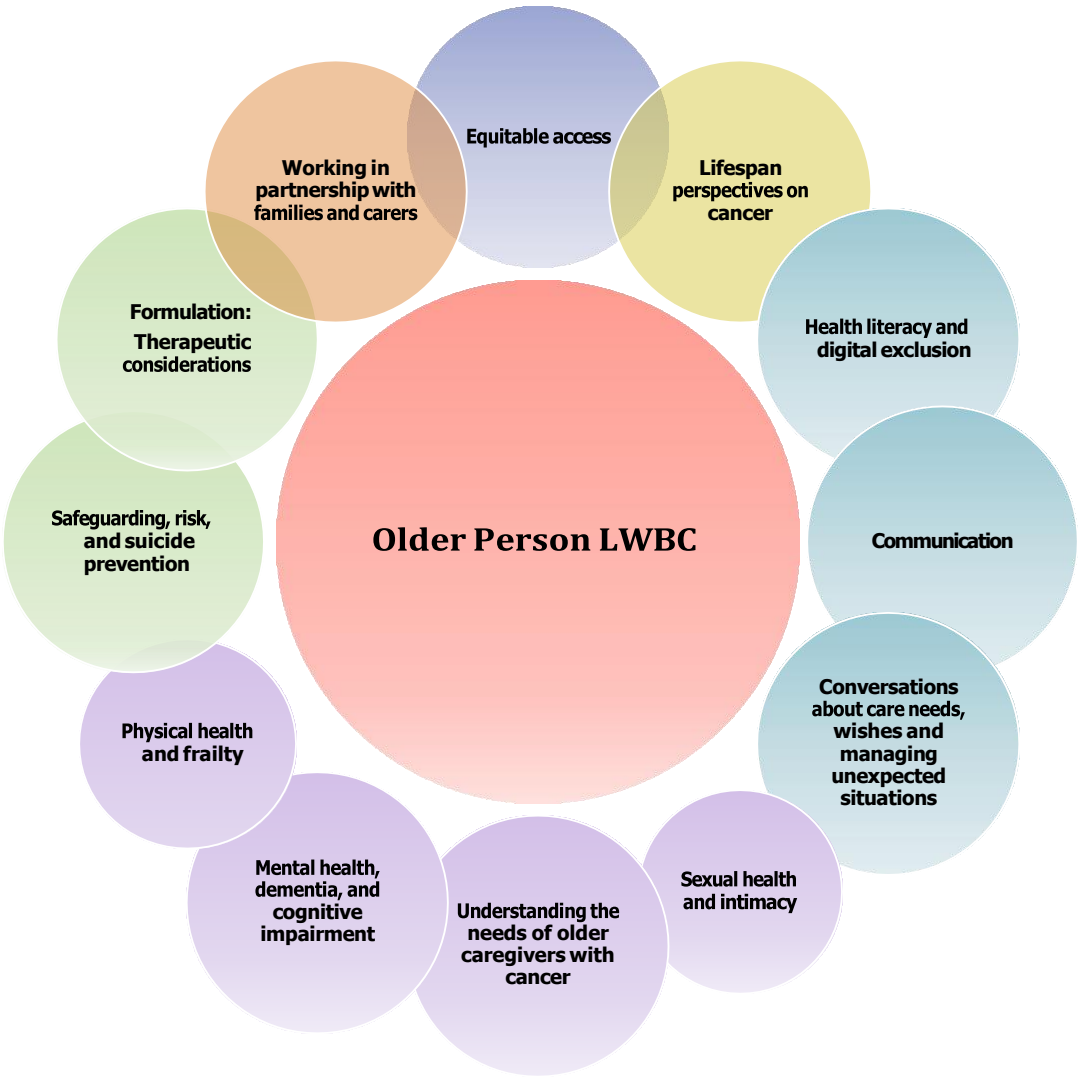
SECTION 2. Understanding the psychosocial needs of older people

This section looks at how services can understand and accommodate the diverse and varied psychosocial needs of older people living with and beyond cancer. This section is relevant to all healthcare professionals working with people with cancer. The final subsection 'case formulation' is most likely to be relevant to healthcare professionals providing support at the specialist level.

This section includes 12 sub-sections, each dedicated to key themes that impact on the experience of care and psychosocial outcomes as identified by literature, research, and the stories of older people living with and beyond cancer, their families and carers. (see Figure 4).

Figure 4

Key themes identified as important for improving psychosocial outcomes for older people living with cancer, their families and carers.



2.1 Lifespan perspectives on cancer

Ageing is a process, not a state (Laidlaw et al., 2016) and chronological age is not a proxy for health status or care needs (Kotschy et al., 2024).

Gerotranscendence is the developmental theory of healthy ageing that suggests as older adults mature, their mindsets evolve, changing the way they interpret the world around them (Abreu et al., 2023; Tornstam, 2011). Gerotranscendence can be described as a state of mind and is linked to perspective shifts across several dimensions including: cosmic (feeling connected or sense of belonging), coherence (self-awareness and self-acceptance) and solitude (looking inward and finding inner peace; Tornstam, 2011). Research shows that gerotranscendence is positively linked to mental well-being and life satisfaction and can be accelerated following major life events such as illness and crises that promote existential reflections about life, our purpose in life and meaning making (Abreu et al., 2023). A greater appreciation of life, positive changes in relating to others, and spiritual change can be particularly powerful changes following cancer for older people.

An older person's social history and context play an important role in how their beliefs about illness, health, healthcare, and healthcare professionals are constructed (Dow, 2022). With the fastest growing age group in the UK population being those aged 80 years and over (Centre for Ageing Better, 2023), many older people alive today will have lived through pivotal developments in healthcare such as the inception of the NHS and the introduction of chemotherapies, radiotherapies, surgical cancer treatments, and vaccines. Not only does this impact the way older people seek and receive healthcare (e.g., holding stoic attitudes, not wanting to be burdensome, being passive recipients of care), but it also impacts how many older people will have experienced illness and loss historically (e.g., some older people may have cared for their parents at home before treatments and community palliative care or end-of-life services were developed; Winnicott, 2016).

Post traumatic growth refers to the "positive psychological changes experienced as a result of the struggle with trauma or highly challenging situations" (Tedeschi et al., 2018, p. 3). Post traumatic growth is linked to several positive outcomes, including reduced psychological distress, and improved physical health, interpersonal relations, self-esteem, and outlook on life (Kadri et al., 2022). Services can foster recovery and growth by focusing efforts on increasing social inclusion and community links to support, providing psychoeducation and prehabilitation, acknowledging the potentially traumatic impact of cancer and providing pastoral care through the holistic assessment of needs and development of relevant action or support plans.

Older people with cancer may be experiencing a range of psychological issues including: managing anxiety between initial investigations and diagnosis, difficulties coming to terms with the diagnosis and treatment, adjusting to changes in physical ability, managing symptoms of the cancer and side effects of treatment such as pain,

sleep and fatigue difficulties, and other individual significant life transitions that might be connected to loss of independence and grief (Macmillan Cancer Support, 2021). For some older people these may include relinquishing a profession or driving licence prematurely, not being able to engage in hobbies or activities of daily living independently or at all, not being able to care for (and anxiety regarding the future for) dependent children, parents or grandchildren, and the psychological process of coming to terms with a different or shortened future. For people at the end of life these concerns might expand to include pain management and dignity-related concerns.

2.2 Increasing health literacy and reducing digital exclusion

This section looks at how health literacy and digital exclusion impact how older people living with and beyond cancer experience psychological distress and help-seeking.

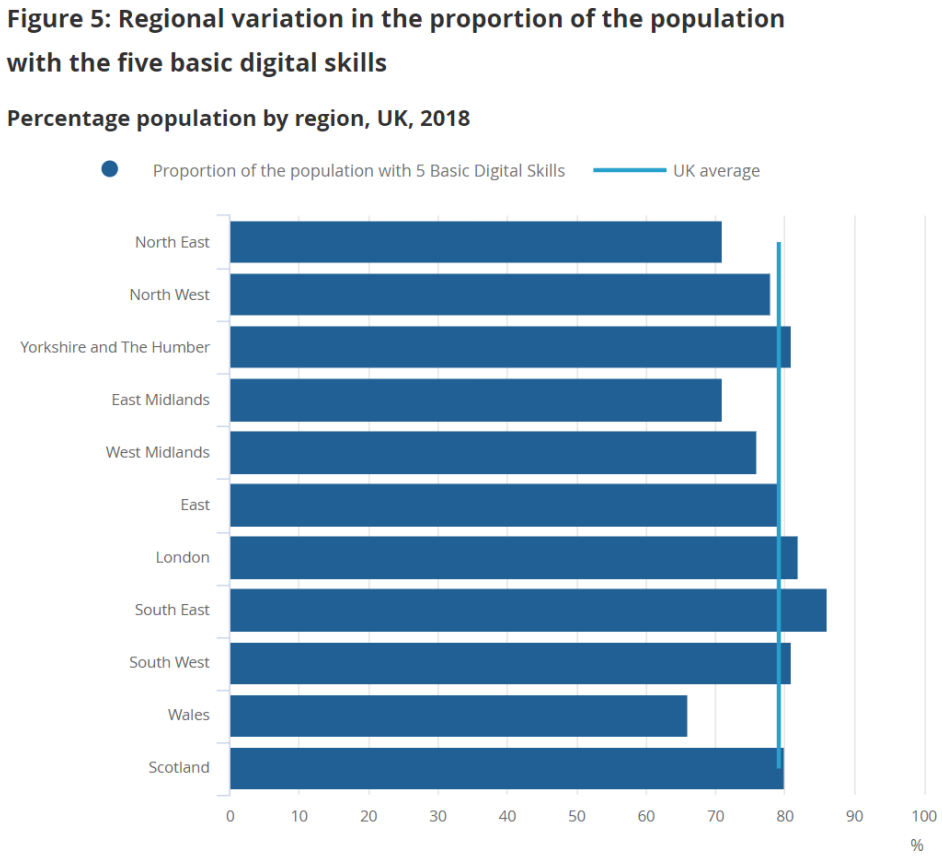
Health literacy is defined as 'the degree to which individuals have the cognitive and social skills to appropriately access, understand and use health information and services to maintain good health' (Paasche-Orlow et al., 2005). Health literacy plays a vital role in cancer care quality and outcomes, with lower health literacy linked to poorer understanding and processing of information related to cancer care (e.g., prevention, diagnosis, prognosis, treatment), worse care experiences, reduced quality of life and increased risk of mortality (Holden et al., 2021).

Approximately 60% of the European population over 65 have low health literacy (Sørensen et al., 2015), exacerbated by age-related physical and cognitive decline, sensory impairments and frailty (Stephenson et al., 2022). Moreover, lower health literacy is more prevalent for older people with intersecting marginalised identities, including people from deprived socioeconomic communities, people with long-term conditions and disabilities, and minority ethnic people (Roberts, 2015). Resultingly, older people within these groups face wider health inequalities, leading to difficulties managing their health and care effectively and increased psychological distress (Gursul, 2022).

Interactions with healthcare services are increasingly dependent on service users having good digital literacy skills (NHS England, 2020b). This barrier to access disproportionally impacts older people as they are most at risk of experiencing digital poverty and exclusion (Roberts, 2015). Digital poverty is defined as 'the inability to interact with the online world fully, when, where, and how an individual needs' (Digital Poverty Alliance, 2024). A recent assessment of digital poverty in the UK found that 1 in 2 older adults are in digital poverty, and 1 in 5 are in severe digital poverty (Deloitte, 2023). Moreover, digital deprivation in the West Midlands is worse than the UK average (see Figure 5 below), with determinants including limited or no digital skills, restricted or no access to internet and devices, and a lack of motivation to develop digital skills (Allmann, 2022).

Figure 5

Comparisons of digital skills by region, UK.



Source: ONS, 2019

Recommendations

The following recommendations were developed from the Agency for Healthcare Research and Quality Health Literacy Universal Precautions Toolkit (2024) and Cheshire and Merseyside Cancer Alliance's 123 Approach to Healthcare Inequalities (2024):

14. Provide clear and accessible written and verbal communication, on topics such as accessing support in the community, health care at home, and the biological, psychological and social impacts of having cancer.
15. Develop lunch and learn sessions for staff to share case studies and create learning opportunities around the health literacy needs of older people.
16. Ensure services promote resources in line with the key focus areas, in formats that suit the older people using those services.
17. Consider a range of factors including intersectionality, neurodivergence, cognitive and sensory impairments, digital exclusion and poverty and cultural differences.

18. Work with older people to co-identify important information and reduce to key points and reinforce (what does the older person in front of you want to know and how do they want to learn this?).
19. Check the older person, family and carers' understanding with teach-back/role play with questions. Asking "would you like to tell me what you've understood from what I've just said?" is more informative than asking "do you understand?".
20. Encourage older people to use resources to help support conversations in healthcare appointments such as 'What Matters to Me: A Workbook for People with Serious Illness' (Ariadne Labs & The Conversation Project, 2021).
21. The current cohort of older people may need to be invited to talk about their experience holistically, as some people may hold beliefs about "wasting professionals' time."
22. Consider each appointment an opportunity to assess understanding of care plans and provide education to the older person, family or carers where appropriate.
23. Reassess concerns and support needs frequently throughout treatment or during each cancer care review (recognising that the situation may have become more complex or anxiety-provoking with co-morbidities more likely to be identified/treated by another healthcare team during cancer treatment than in younger people).
24. Avoid reliance on 'opt-in' methods of managing referrals; these are likely to deny access to the most vulnerable in society including older people, and in particular older people with English as an additional language (or no English) and people with cognitive impairment and learning disabilities.
25. Use multiple systems (to include physical letters or phone calls) to communicate with older people about appointments. Digital systems can be helpful for older people using assistive technologies but disadvantage people without access or ability and people who may need the support of carers to make sense of information.

What do older people know about cancer and cancer treatment? What is the key information we can give?

The current cohort of older people include those born in the 1920s and 1930s who would have experienced significant change with regards to medical care in their early life, including those born before the inception of the NHS in 1948, the first generation of babies more likely born in a hospital than at home (in the 1960s) and those likely to be treated for serious or infectious disease in hospital without their parents allowed to visit frequently or at all, which was common throughout history until the late 1970s. For some older people, undergoing tests and treatment may trigger difficult memories or feelings from that time that require support and potential onward referral (Flaum & Hall, 2013).

It is important to have an awareness of the context within which the current cohort of older people with cancer have grown up (see lifespan perspectives on cancer section). This will have shaped the key messages around illness and health they might be familiar with and might defer to during their cancer journey. Despite cancer risk increasing as we age (Marosi & Köller, 2016), older people's understanding of cancer and cancer treatment is lacking (Estape, 2018). What people know about cancer and cancer treatment is important in gaining informed consent, setting realistic expectations and effectively managing psychological distress (Davies et al., 2020). Moreover, beliefs about cancer influence cancer care experience, quality and outcomes (Macmillan Cancer Support, 2015a).

Older people tend to have lower health literacy, as health was rarely considered outside of illness in their lifetime (Estape, 2018). This may have led to poorer understandings of cancer, particularly in regards to prevention and early detection. In support of this, a large majority of older people, both with and without cancer, do not think that the disease is age-related (Macmillan Cancer Support, 2015a). Moreover, Macmillan reported many older people are confused about available screening options and how to access them, as well as being fearful of cancer treatment. Many of the current cohort of older people may have witnessed their own parents or grandparents experiencing cancer or cancer treatment prior to or at the beginning of chemotherapy treatment becoming widespread in the 1950s.

Macmillan's research (Macmillan Cancer Support, 2015a) also revealed that attitudes towards cancer treatment were more negative amongst older people who had not experienced cancer than those who had. Older people living without cancer were particularly concerned about the consequences of cancer treatment (physical, social and emotional). This uncertainty around the effects of cancer treatment could deter older people from help seeking when symptoms present and accepting treatment once diagnosed. Moreover, it is possible that negative attitudes towards treatment are misinterpreted by clinicians as an inability to tolerate treatment (Flannery et al., 2021), which may be influencing the proportions of older people with cancer who are offered treatment.

The National Patient Cancer Experience Survey (2024) highlighted that older people consistently raised concerns regarding communication and information sharing. More specifically, older people felt that they were not given adequate personalised information about their cancer (diagnosis, prognosis, treatment, interactions with long-term conditions, long-term impact, survivorship) and how to look after themselves at home. Further, inter-professional communication and information sharing across systems were reported as lacking, leading to poorly coordinated care and reduced support, particularly for older people with co-morbidities.

Effective information sharing and communication are especially salient when working with older people affected by cancer. As older people are less likely to search for information following a diagnosis (Macmillan Cancer Support, 2015a), their decision-making is heavily influenced by their conversations with healthcare professionals.

> "The oncologist tried very hard to explain what the alternative treatment options were, which were an operation or chemotherapy. It was explained that the operation would cause lots of broken bones, which was helpful to know and contributed to the decision to opt for chemotherapy. I can't remember exactly when immunotherapy was first mentioned, but we learnt more about it from a staff member during a chemotherapy session. When the treatment was changed to immunotherapy, the difference in side effects was like night and day."
>
> - Quote from Older Person with Cancer receiving treatment in the West Midlands.

Given the implications on care experiences and outcomes, practitioners should strive to assess older peoples' understanding and unmet information/health education needs regularly throughout the cancer pathway. Tools such as holistic needs assessments and the distress thermometer (Macmillan Cancer Support, 2019a), and techniques like teach-back and chunk and check (NHS Health Education England, 2020) may be beneficial in supporting professionals to ensure that gaps in knowledge that may impact on psychosocial experience can be addressed.

Lastly, evidence suggests that older people are more likely to believe that they can cope with cancer in comparison to working-aged people, which may stem from wanting to maintain their independence (Macmillan Cancer Support, 2015a). Although it is often assumed that older people are less comfortable seeking support, Macmillan found that requesting help was not a barrier for older people living with cancer. Despite this, older people continue to receive fewer referrals for psychosocial support than their younger counterparts. It is possible that 'stoic attitudes' towards coping underpinned by fear of losing independence might influence the outcomes of holistic needs assessments for the current cohort of older people. As such, healthcare professionals should endeavour to consider these concerns within their interactions with older people living with and beyond cancer and be attuned to the ways in which age, perceptions of age held by the older person themselves and

perceptions of age held by the service and professionals might be a factor in the process or outcome of healthcare interactions.

Recommendations

26. Healthcare professionals at the universal level should focus their attention on providing key information in a range of formats across the following domains:
    a. **Age-related risk of cancer and complications:** Health literacy information regarding risks, signs and symptoms of disease progression or complications that might arise during treatment and what to do/when advice given to reduce anxiety and support future planning should be provided to older people as a preventative measure.
    b. **Treatment myths:** More case studies could be used in infographics/leaflets disseminated within healthcare services, and increased provision of older adults facilitating peer support or Living with and Beyond Cancer workshops and wellbeing events within the community to dispel some of the preconceived misconceptions about cancer treatments for older people.
    c. **Information sharing that encourages participation in care**: Holistic needs assessments and co-produced support plans are required to inform and promote information sharing between clinicians and older people with cancer about their diagnosis, prognosis, treatment, co-morbidities, at-home care, and survivorship. Making use of resources (see Ariadne Labs & The Conversation Project, 2021) can empower older people and their families and carers in preparing for and getting the most out of appointments as active participants of rather than passive recipients of healthcare.
    d. **Further specialist support:** Better signposting to and awareness of specialist psychosocial support services amongst healthcare staff, with an emphasis on protecting independence, and local community support, providing physical leaflets and telephone numbers where someone is unlikely to be able to access digital resources such as the Cancer Care map.

2.3 Communication

This section looks at how communication may need to be adapted to reduce psychological distress for older people living with and beyond cancer.

For older people with cancer, each interaction with a healthcare professional is an opportunity to prevent, identify or alleviate distress. By offering a person-centred, trauma-informed approach within cancer services, older people can have more equitable access to and a better experience of care.

How a person would like to be referred to in sessions or appointments and how to pronounce their name are good introductory questions. Ask questions that support the person to feel comfortable and do not make assumptions about how they see themselves or which aspects of their identity are most important or prominent to them. The comprehensive Geriatric Assessment (see Getting It Right First Time [GIRFT] & British Geriatrics Society, 2023) suggests asking the patient "what matters to you?" as a starting point.

If using screening tools or formal written assessment measures, it is important to clarify the reading, writing and receptive and expressive language skills of the person, which may change with age. Consider the use of an interpreter and translated materials even if the person can speak English as a second or third language. If the person is unable to read or has fluctuating capacity and needs family/carer support to make informed decisions, consider producing written information in the language of the main carer.

Recommendations

There are practical adaptations healthcare professionals can make to communicate more effectively with older people with cancer (adapted from National Institute on Aging, 2023a, 2023b):

27. Documentation should invite people to bring hearing aids or reading glasses to support communication and ability to fully engage with information.
28. Establish trust and a rapport by speaking to older people with compassion, dignity and respect, identifying preferred terms from the offset.
29. Explain who the healthcare professionals present are and the purpose of appointments/telephone calls (there may be a need to do this more than once during a conversation).
30. Assess and address communication needs throughout interactions, ask if patients can hear/see information being shared on screens, and offer frequent opportunities to clarify/check understanding etc.
31. Practice compassion within interactions (speak slowly and plainly, be patient and aware of differences in processing times for older people, especially those with learning disabilities or English as a second language).
32. Ask open ended questions but be prepared to use yes/no and multiple-choice questions to support someone with cognitive impairment.

33. Direct body language and turn towards patients when speaking.
34. Provide written and verbal communications, ask for preferences, and consider the involvement of family and carers during or at the end of appointments.
35. Be culturally sensitive and aware of differing needs.
36. When consent has been given, include family members and carers in discussions.
37. When broaching sensitive topics, take a universal approach “Many people experience...”

The Cancer Alliance is currently reviewing the use of end of treatment summaries (EOTS) and cancer care reviews. It is recommended that the Cancer Alliance consider the following:

38. Co-production with the older person and their carer/family members before an EOTS is sent to understand the usefulness of this document and reduce the time taken in subsequent appointments with healthcare professionals outside of cancer trying to make sense of the content of EOTS (‘de-coding’).
39. The development of co-produced standardised EOT templates that are specific to the West Midlands population.

2.4 Conversations about care needs, wishes and managing unexpected situations

This section focuses on conversations that might prevent or alleviate distress in the management of unexpected and anticipated cancer-related difficulties, by supporting people to think about and plan for care needs in advance.

Planning for the future should be part of the beginning of an older person's journey through cancer services, rather than at the end of treatment, and can occur over several appointments with a trusted healthcare professional. Whilst the specific nature of the plans might shift over time with changing priorities, it is important to support older people to consider what might be important to them in thinking about life with and beyond cancer, as well as at the end of life.

Families and carers can be supported to understand the wishes of the person with cancer and have discussions together, considering risks and benefits to decision making about the future. The term 'fun guarding' refers to protecting the rights and wishes of older people to continue to experience joy and pleasure (British Geriatrics Society, 2019). This is particularly important for people with limited or fluctuating capacity, people with moderate frailty, people with communication difficulties, and/or people living in residential settings.

Many older people will have made plans for death, but not for dying (Hanratty et al., 2013). It is an assumption older people will approach a healthcare professional in their own stage of readiness to think about the end of their life.

Recommendations

The following list of recommendations is developed from the person-centred future planning guidance by Macmillan Cancer Support (2017a), the religious and spiritual needs guidance by Cancer Research UK (2022), and the NICE guidelines for healthcare professionals supporting people growing older with learning disabilities in planning for the future (NICE, 2018a, 2019):

40. Ensure planning is person-led, and where appropriate include family members, carers and advocates.
41. Ensure plans are co-produced with a practitioner that is well known and trusted by the person and their wider network.
42. Seek and include input from practitioners with knowledge and awareness of local resources.
43. Consider an older person's life holistically. Areas of focus in a plan should be on housing suitability, monitoring and addressing changing needs, capabilities and capacity (to include caring for others/pets, physical mobility, cognition, frailty), building and maintaining support networks (carer assessments, support needs of family members), money management, legal arrangements (in relation to driving licence, wills, power of attorney, resuscitation wishes) and (if applicable) end of life planning.

44. Include relevant contingency planning and education on potential sudden changes/crises (illness or death of carer, delirium, or unexpected hospital admission during cancer treatment) to empower older people and family and carers to feel more knowledgeable about what to do and how to cope with uncertainty and change if a challenge arises.
45. Provide ‘packing lists’ to support people who may need to be away from home for treatment to know what to bring with them to increase their comfort levels and provide familiarity and reassurance at a vulnerable time.
46. Offer repeated opportunities for older people to express their religious or spiritual needs during their final weeks, and these preferences should be recorded on case notes and respected by all staff.
47. Older people may want to consider sharing their experiences and beliefs with religious or spiritual leaders during their final weeks in particular.
48. Foster an environment where discussing, preparing and planning for death is normalised, as honest and open conversations about dying can facilitate dying ‘well.’
49. Encourage re-framing of perspectives on planning for death, moving from ideas of defeatism to regaining control and being able to focus on remaining life.
50. If cancer is palliative, the opportunity to discuss plans, preferences and the emotional impact of end of treatment, death and dying should be created.

2.5 Sexual health and intimacy

Sexual health is a state of physical, mental, and social well-being, and encompasses attitudes and behaviours related to sexuality (World Health Organization [WHO], 2006). Intimacy is defined as feeling connected or close to others, physically and emotionally (National Institute on Aging, 2022). Sexual health and intimacy are important drivers for quality of life and well-being among older adults (Smith et al., 2019), and so it is important to consider how these needs can be addressed.

It is commonly misconstrued that sexual health and intimacy become less relevant as we age, however, data from the English Longitudinal Study of Ageing indicates that many older men and women remain sexually active into their 80s and 90s (Lee et al., 2016). Importantly, self-reported sexual health and intimacy concerns were seen to increase with age. Moreover, for older people facing higher instances of poor physical and mental health, like minority ethnic, sex, gender and socioeconomic groups, sexual health and intimacy challenges are more likely (Leon & Callaghan, 2021; National Institute on Aging, 2022). For example, for older people with long-term conditions, sexual activity, function, and satisfaction were significantly reduced compared to their healthier counterparts (Lee et al., 2016), suggesting a potential gap in how the sexual health needs of older people are assessed and addressed in healthcare services.

Like many chronic illnesses, cancer has a profound impact on many relationships, particularly intimate ones, impacting sex and intimacy, with effects persisting long after treatment (Maggie's, 2022). Psychosexual care is relevant for all cancer groups irrespective of whether treatment directly impacts sexual organs, sex hormones and/or body image (e.g., mastectomies and colostomies; McDowell et al., 2024). For instance, cancer and cancer treatment may induce sensory, physical (e.g., incontinence) and psychological changes that impact directly on sexual desire and function (Carter et al., 2018), whereas acute side effects like hair loss, fatigue, and pain may impact self-esteem, confidence, and distress levels, thus having an indirect effect on sex and intimacy (Frederick et al., 2023). Moreover, research shows that common side effects of cancer treatments like neuropathic pain can place significant restraints on older people's intimate relationships (e.g., holding a loved one's hand is no longer comfortable due to pain; Sofaer-Bennett et al., 2007). Despite this, less than half of people living with cancer received any information about how cancer might impact sexual well-being (Flynn et al., 2012), with even fewer (just 10%) having their sexual health concerns assessed or sexual dysfunction treated (22%; Reese et al., 2017a).

Unmet sexual health needs of people living with and beyond cancer appear to be rooted in poor communication, with healthcare professionals seldom discussing sexual health and intimacy with their older cancer patients, citing barriers like discomfort and lack of knowledge (Barbera et al., 2017; Reese et al., 2017b).

A systematic review found that patient-reported barriers to help-seeking often stemmed from the difficulties also cited by professionals (Dai et al., 2020). For example, perceiving professionals' discomfort led to a reluctance in the patient to raise concerns and compounded internalised feelings of embarrassment among those living with or beyond cancer. Moreover, many felt professionals were not equipped to address and treat their concerns effectively and there were practical barriers to such conversations including lack of privacy available.

Recommendations

51. The psychological impact of difficulties related to cancer, intimate relationships, sexual health and intimacy should be included in holistic needs assessments and onward referral to psychological support services at the enhanced or specialist level made accordingly.
    a. Signposting to organisations specialising in relationship counselling such as Relate.
52. Training in how to offer a discussion of the sexual health and intimacy needs of older people with cancer should be incorporated into existing training for healthcare professionals working at the enhanced and specialist level.
53. Where areas of the West Midlands are served by dedicated psychosexual services these should be identified for onward referral where appropriate.

2.6 Understanding the needs of older caregivers with cancer

In England and Wales, older people provide the most hours of unpaid caregiving, equating to nearly 2 million people aged 65 years and older (ONS, 2023a). Moreover, 55% of older caregivers are living with a long-term condition or disability themselves (Age UK, 2023a). However, to date, no research has explored the challenges faced by older caregivers with cancer and the NHS website has a dedicated advice page for younger but not older carers (NHS, 2023). As 65% of cancer caregivers cite unmet needs (Macmillan Cancer Support, 2016), it is likely to be a more complex and nuanced situation for an older person with cancer themselves.

Prospective qualitative research (Travis, 2024) tells us that older people with cancer caring for people with dementia face difficulties in the following domains:

- Difficulties attending appointments (finding respite care, coordinating around caregiving appointments)
- Unmet support needs: cited less need for information and more for emotional and practical support but were often unsure where to find it.
- Different priorities: caregiving comes before cancer, which carries implications in help-seeking and decision-making regarding treatment.

The practical difficulties faced by older people caring for other older people can include short appointment times and not enough time to holistically discuss aspects of care, changes in family dynamics meaning that care is not easily shared by children and difficulties adjusting to new roles or tasks as caregiver/recipient (Alcañiz-Garrán et al., 2021; Schorch et al., 2016).

The psychological impact of being an older caregiver for another older person includes increased irritability, apathy and associated shame (Tsai et al., 2021) and higher risks of exhaustion, loss of identity/spare time and loneliness (Reis da Silva, 2024). There is also a significant financial impact on access to benefits as noted on the government benefits website “You can't receive the full amount of both Carer's Allowance and State Pension simultaneously” (GOV UK, 2024).

> “We always had discussions about care and treatment when both of us were present, and any decisions about care were always made jointly. When I was diagnosed with cancer, I couldn't have an operation because I’m looking after my partner”.
>
> - Quote from Older Person with Cancer caring for their spouse.

"My first thought when I was diagnosed the first time was how the family would manage if it was the worst scenario. In the second diagnosis, my chief concern was for my husband as he had then been diagnosed with dementia and I was his main carer ... My hospital care was very good, although it was 'cancer' centred. My husband was ill, so I did not have time to attend support groups. More support in the home and an understanding of the problems I faced caring for my sick husband would have gone a long way. These problems were both emotional and physical."

- Quote from Older Person with Cancer caring for their spouse, Macmillan No One Overlooked Report.

Recommendations

54. The complexity of the role and context for an older people with cancer who is also a caregiver should form part of any needs assessments that might take place during the cancer journey such as during health needs assessments, cancer care reviews, primary care mental health or psycho-oncology assessments.
    a. Healthcare professionals should work collaboratively with an older person with cancer and caregiving responsibilities to identify ways to support them in continuing or reducing (dependant on need and wishes) their caregiving responsibilities alongside their own cancer care and treatment.
55. Older people with cancer who are also caregivers should be signposted to appropriate local and regional support services which may include the local authority carers support service as well as organisations such as Carers UK, Age UK, Alzheimer's Society and Dementia UK.

2.7 Mental health, dementia, and cognitive impairment

Older people and people from the most income deprived quintiles are less likely to receive an early diagnosis when they have cancer and there is an increased risk of anxiety and depression amongst people with a late-stage diagnosis (Macmillan Cancer Support, 2019b). There is a greater incidence of anxiety and depression amongst people with cancers that typically have a poorer prognosis (Forbes et al., 2024).

People with dementia are also more likely to be diagnosed with cancer at a later stage of disease, have more treatment complications and receive less treatment (Griffiths et al., 2020). Approximately 7% of people in England aged 65 have a diagnosis of dementia, rising to 17% at 80 years of age (Wittenberg et al., 2019).

Dementia is a significant impairment in cognitive functioning severe enough to interfere with day-to-day living, and often involves difficulties with memory, reasoning and language (Kurella Tamura & Yaffe, 2011). Similarly, mild cognitive impairment is characterised by cognitive decline that exceeds expected age-related changes, however, it does not necessarily affect individuals' ability to live independently (Hugo & Ganguli, 2014) and may not develop into a neurodegenerative condition such as dementia. People with dementia or cognitive impairment may not have had a diagnosis and therefore there may have been little or no advance notice of additional need prior to a first appointment.

Assessing the cancer care needs of older people with dementia and cognitive impairment can be complex and there is little research on good practice in decision making for this growing cohort of older people (Griffiths et al., 2020). How treatment impacts on pre-existing cognitive impairment is also poorly understood and under researched (Loh et al., 2016). The impact of cancer treatment on cognitive function appears to vary depending on several factors including the type of treatment, the individual’s overall health and co-morbidities, and the stage of dementia (Magnuson et al., 2021).

Some older people with dementia or cognitive impairment may lack insight and be unable to give accurate reports of their symptoms, activity levels, abilities and difficulties and any notable changes over time. Sometimes the person may recognise the presence of cognitive difficulties but they or their family might be unable to find the language to express more subtle changes they have noticed or to express worries about how cancer treatment might impact on dementia progression. It can be helpful to invite family and carers into appointments for history taking or assessments, and when planning care or making treatment decisions (Cancer Research UK, 2018).

Some older people accessing cancer treatment might be experiencing co-morbid mental health difficulties such as low mood and anxiety and cognitive changes such as difficulty planning or following sequences that require neuropsychological

assessment in secondary care mental health services or memory clinics. Providing information about what is and is not known about the impact of a specific treatment on cognition (in the short and long term) to the family and wider healthcare professionals working with the older person can ensure that decisions about whether to offer or take part in a neuropsychological assessment whilst undergoing cancer treatment can be made on a case-by-case basis. Information about whether there is a risk that treatment or treatment side effects or complications could worsen the symptoms of dementia can also support older people and their families and carers in making informed decisions about and giving consent to different treatment options.

The Royal College Inpatient Standards for Older Adult Mental Health (Quality Network for Older Adult Mental Health Services Royal College of Psychiatrists' Centre for Quality Improvement, 2019) suggests environmental standards that could be adapted to improve the experience of care for older people with cancer and dementia or cognitive impairment coming into hospital, such as ensuring that healthcare staff providing cancer care are clearly identifiable, and giving older people admitted to hospital during cancer treatment a "welcome pack" to orientate them to the setting with key information about facilities, staff and support, which could also include practical information for family and carers about the routines of the ward and where to access information or support.

For people with learning disabilities, the Confidential Inquiry into the Deaths of People with Learning Disabilities found that services often fail to adapt practice to suit their needs (Heslop et al. 2014). Additional needs that are more likely amongst adults with learning disabilities include sensory impairments (sight/hearing), cognitive impairments (including neurodegenerative conditions such as dementia) and physical and mental health difficulties (NICE, 2018a). Moreover, older people with learning disabilities are more likely to have unmet social needs due to being moved to older people's residential services earlier than necessary, impacting their communication, physical activity levels and opportunities for connection.

People with learning disabilities experience later cancer diagnoses, and poorer screening uptakes (Morris & Julian, 2024). The Confidential Inquiry into the deaths of people with learning disabilities report (Heslop et al., 2014) found that healthcare staff were less likely to investigate symptoms amongst people with learning disabilities. Families of people with learning disabilities and paid carers reported feeling that doctors did not take them seriously.

The support needs of people with learning disabilities echo those of the general population (Tuffrey-Wijne, 2017). For instance, these include not to live in pain, to have familiar people present to support them, to feel listened to and involved in their care and treatment. People with learning disabilities also have unique needs described above (differences in communication and comprehension, cognitive and sensory impairments, multi-morbidity, unmet social needs.)

For older people with severe and enduring mental health needs services may consider the reasonable adjustments referred to in the NHS England (2024) guidance Improving the Physical Health of People Living with Severe Mental Illness such as the timing/length of the support offered, different methods of inviting someone to take part in support groups or attend appointments, location of the appointment or group or whether care needs to be provided in the community or care or residential home.

Recommendations

56. When assessing how an older person has been coping with activities of daily living prior to cancer diagnosis, healthcare professionals should consider inviting family and carers to contribute to discussions.
57. Healthcare professionals should invite older people and family and carers to discuss their concerns about cancer in relation to existing cognitive difficulties and work in partnership with older adult mental health or learning disability teams to plan for how to monitor the impact of treatment on symptoms so that care can be reviewed as necessary.
58. Healthcare professionals should signpost to sources of emotional support in relation to concerns about how cognition might be impacted by cancer treatment and how dementia might impact on decisions about treatment such as Macmillan's cancer and dementia booklet (Macmillan Cancer Support, 2020a), and guide for carers (Macmillan Cancer Support, 2017b).
59. Healthcare professionals should encourage older people and families and carers to make contingency plans that will support a person-centred approach to care for someone with mental health, learning disabilities or cognitive impairment for instance, prepare a bag with important items of comfort and familiarity for unplanned admissions to hospital, complete the "This is Me" booklet and consider making plans for the future such as wills and power of attorney (See Conversations about care needs, wishes, and managing unexpected situations section).
60. Acute services should review the information provided to older people on admission to hospital for cancer treatment or the management of cancer-related complications and co-produce resource packs with key information for the duration of the stay such as standard routines on the ward, telephone numbers for family to call and who to seek support from.
61. For healthcare professionals working with older people with cancer and learning disability or cognitive impairment there may be specific considerations in respect of consent to treatment and capacity (British Psychological Society, 2019). Adjustments can be made to clinical practice to attempt to enhance capacity such as longer and additional appointments in which the healthcare professionals:

a. Use simple, everyday words to explain the necessary information and ensure the older person/the person with lasting power of attorney for health and welfare understands, paraphrasing where necessary.
b. Offer information in shorter, more digestible and easier to follow chunks.
c. Provide short written information in the first language of the patient/the person with lasting power of attorney for health and welfare if literate.
d. Use symbols or pictures to represent the key areas where literacy is an issue.
e. Consider a supportive third party who can reinforce necessary learning where appropriate.
f. Consider advice or input from a speech and language therapist for instance regarding assistive technologies that may support these conversations.
g. Allow flexibility regarding scheduling and goals of care and prepare for shortened or unpredictable duration or frequency of therapy sessions.

62. Consider utilising local clinical ethics committees, where available, for support where best interest decisions are complex and/or contested.
63. Healthcare professionals at the universal level can support older people with cancer and families to complete health passports such as “This is Me;” a tool to communicate essential information about the person with cognitive impairment if they are unable to share it directly (Alzheimer’s Society, 2021).
64. Healthcare professionals can signpost to and find support and information in resources such as the Macmillan and Dementia UK guides to cancer and dementia (for people with cancer and for carers; 2017b, 2020b)
65. Audit the use of holistic needs assessments at key intervals through the older person’s journey with cancer services (National Institute for Health and Care Excellence [NICE], 2004).

2.8 Physical health and frailty

Many older people with cancer are living with frailty, and health difficulties such as chronic pain, fatigue and continence difficulties alongside or because of cancer and its treatment (Cancer Research UK, 2018).

Healthcare professionals tend to underestimate the prevalence of pain following cancer treatment and do not agree on whose role it is to inform people of the potential for chronic pain after treatment (Armoogum et al., 2024). In a survey of 106 healthcare professionals working with people with cancer, almost all (93%) felt that it was important for people to aware of the possibility of pain following treatment before treatment begins. However, 46% thought that it was the role of specialist pain services to inform people that their pain could be related to cancer (i.e. this information would potentially be accessible several months following treatment completion, not beforehand), meaning that older people are likely to be unprepared and ill-equipped to respond to or ask for support for cancer-related pain following treatment.

The recent frailty guidance for oncology services published by the Royal College Joint Collegiate Council for Oncology (JCCO), in association with the British Geriatrics Society, the International Society of Geriatric Oncology and Macmillan Cancer Support suggests that “each step in the cancer pathway is an opportunity for assessing and managing frailty” and “frailty is everyone’s business” (JCCO, 2023).

The International Society of Geriatric Oncology recommends the routine use of a Clinical Frailty Scale and the NHS Getting it Right First Time programme highlights that the first step in providing better care for older people with frailty is to ensure all people over 65 have a frailty assessment completed at point of referral including emergency referral, at outpatient clinic and/or on arrival at hospital for emergency or planned care (BGS & GIRFT, 2023).

The Rockwood Clinical Frailty Score looks at how the person was functioning in their life in the preceding two weeks and should form an integral part of assessments on day one of hospital admissions (GIRFT & BGS, 2023). As frailty can be understood on a spectrum (Hopper, 2021) establishing a baseline using and planning interventions designed to preserve independence, physical function, and cognition can help to prevent worsening frailty following a stay in hospital and potentially reverse it (Dent et al., 2019).

The relationship between anxiety and depression and frailty is bidirectional (Soysal et al., 2017). Older people with frailty are less likely to be offered curative treatment after surgery and are likely to experience more serious complications following treatment (Cai et al., 2022). Older people with frailty are four times more likely to experience anxiety and depression.

Recommendations

66. WMCA to lead stakeholders through a process of agreeing system-wide best practice in relation to:
    a. which settings and which professionals are best equipped to discuss the potential for post treatment pain (and late effects).
    b. developing local knowledge of appropriate resources and sources of support for fatigue, pain and sleep difficulties, which are the most common problems reported by older people on the Quality of Life survey (NHS, 2024) in the West Midlands (60-69 years; 85%, 92.6%, 73.2%; 70-79 years; 85.7%, 94.2%, 76.5%; 80+ years; 79%, 92%, 74.1% respectively).
67. Further recommendations to support people with cancer with sleep and fatigue difficulties are within the recommendations of WMCA Mapping Report (Gürpınar et al., 2023).
68. Healthcare professionals at the universal level should be aware of the physical comfort and pain levels of the older person in an appointment and give permission for moving around or standing (for example to manage symptoms of chronic pain).
69. Healthcare professionals should strive to include all relevant health information within referrals to reduce duplication for older people (e.g., sharing the results of samples taken by one part of the healthcare system such as urgent care, with the GP and continence team to minimise physical discomfort for older people living with frailty in being asked to provide multiple samples.
70. Healthcare professionals at the enhanced and specialist levels should be provided with training on how to talk about the more emotive/sensitive potential health effects of cancer and side effects of treatment within level two training (specifically for the cancer workforce), long term conditions top up training (for the Talking Therapies workforce) and in an induction that meets the standards of the British Psychosocial Oncology Society and the Division of Clinical Psychology's Faculty for Oncology and Palliative Care (for practitioner psychologists).
71. Older people's cancer champions to support work to embed frailty assessments in clinical pathways for older people coming into hospital for or during cancer treatment
    a. Consider the recruitment of older people's Experts by Experience to work alongside older people's cancer champions, and the involvement of EDI leads/teams in working to embed, develop and support people in these roles within services.

2.9 Safeguarding, risk and suicide prevention

The Care Act 2014 sets out the statutory duty of healthcare professionals to safeguard people from abuse or neglect, which might look different for older people. For instance, older people may be more likely to be targeted by financial scams than younger age adults. People aged 85 and above are much more likely to be the subject of a safeguarding enquiry (Age UK, 2023b) safeguarding order protecting people from abuse and neglect.

In England and Wales people who live in the most deprived areas are twice as likely to die by suicide than those living in the least deprived (ONS, 2017). Over the last five years in the West Midlands, the number of people who die by suicide has either been higher than or the same as the England and Wales average (ONS, 2023b). Moreover, for people diagnosed with cancers with poor survival rates, suicide rates are 2.4 times higher than matched controls (ONS, 2022).

The evidence suggests several risk factors linked to suicide including physical illness, financial difficulty and economic adversity, harmful gambling, substance misuse, domestic abuse, social isolation and loneliness in addition to the social determinants of health such as housing, poverty, employment and education (Department of Health and Social Care, 2023. Cancer services should develop systems to identify and respond to risk factors amongst older people that support a multiagency approach to safeguarding and are based on the principles of collaboration and partnership with people and where appropriate families/carers (Social Care Institute for Excellence, 2015). Resources such as the Domestic Abuse Toolkit (Macmillan Cancer Support, 2024b) may be beneficial in supporting professionals to safeguard older people affected by cancer from abuse and neglect.

Risk may need to be conceptualised differently when working with older people, who are less likely to engage in self-harm behaviours such as cutting and are more likely to engage in self-neglecting behaviours such as not renewing prescription medication, missing healthcare appointments and not eating or drinking sufficiently to remain well. Living with or beyond cancer can contribute to the increased risk of self-harm and suicide amongst older people, which has been linked to factors including bereavement (Koo et al., 2017a), loneliness, perception of being a burden to others, loss of control (Troya et al., 2019) and feeling abandoned and lacking purpose or meaning in life (Wand et al., 2019).

Older people are more likely to die by suicide than younger age adults and self-poisoning with medication is the most common method although older people are not a homogenous group and there are differences amongst those 65-75 and older people (Koo et al., 2017b). There are also differences between the sexes with men over 90 and women under 55 more likely to die by suicide than at any other age (ONS, 2023b).

The following might be considered warning signs that an older person with cancer might be considering suicide (adapted from; De Leo 2022):

- The older person appears or reports feeling sad or depressed most of the time or feeling anxious, agitated or unable to sleep or sleeping all the time.
- Reports or is observed by health or social care professional or family/carers to have frequent and dramatic mood swings.
- Is observed to be neglecting personal hygiene and no longer paying attention to physical appearance as they once did.
- Does not want to see friends or family and no longer has a social life.
- Expresses disproportionate feelings of guilt or shame.
- Loses interest in food/reduced food and fluid intake with no physical cause.
- Has appreciably increased consumption of cigarettes and alcohol.
- Puts aside pills and other non-therapeutic drugs with no clear rationale.

Although the below behaviours should be seen in context for someone reflecting on their stage of life and current circumstances living with cancer or accessing palliative cancer care, a comprehensive risk assessment should also be considered if someone with cancer is showing the signs above in addition to:

- Talking about death (for example, in the context of wanting suffering to end 'I've had enough' or 'it makes no sense to continue').
- Suddenly taking active steps to 'put business in order' such as labelling own things, making a will or changing a will, giving away objects of emotional importance and unexpectedly visiting relatives and friends as if to say goodbye.

Recommendations

72. Healthcare professionals working at the universal level should be able offer basic safety planning to include:
    a. contact information for the local mental health crisis team.
    b. how to access specialist advice from or escalate concerns to local primary or secondary care services for older people and social care/ safeguarding leads.
    c. informing all prescribers in the person's care plan across primary, secondary, and tertiary care settings.
73. Healthcare professionals working at the enhanced level should have access to training on appropriate adaptations to assessments of risk in older people with cancer as part of level two training programmes.
    a. Healthcare professionals at the specialist level should have access to training on appropriate adaptations to assessments of risk in older people with cancer (as part of LTC top-up training for staff in Talking Therapies for anxiety and depression and/or clinical psychology

training programmes), with knowledge of local support pathways and resources for signposting within both the NHS and local voluntary and community organisations.

b. Further advice is available from International Association for Suicide Prevention (2024) and Zero Suicide Alliance (2024).
c. Trust-level considerations should be made regarding implementing suicide awareness and prevention education as part of statutory and mandatory training for all staff.
d. Be able to identify signs of domestic abuse and neglect in older people with cancer, and signpost them to appropriate local services.

2.10 Formulation: Therapeutic considerations and case conceptualisation

Case conceptualisation (herein referred to as formulation) is an important process for understanding people's difficulties in context. A good formulation developed in partnership with an older person with cancer (and potentially their family and carers) is a way of understanding how a person's experiences and beliefs might relate to the difficulties that they face, makes sense to the person with cancer and fosters hope for positive, meaningful change or increased understanding. For NHS Talking Therapies staff working with older people, guidance for developing formulations can be found in the Positive Practice Guide (BABCP, 2024).

Formulation with older people with cancer can help to identify and reduce psychological distress by recognising and building upon their strengths. In cancer care, a good formulation should seek to integrate the personal meaning of having cancer into the person's life story rather than be a list of factors including cancer and preceding life events that have occurred (British Psychological Society, 2011).

Older people with varying spiritual, religious or philosophical beliefs may have their own understandings of why they have cancer, whether cancer treatment or therapy for cancer-related distress is appropriate or likely to be received with stigma and shame. How distress, disease and disability may be experienced can be linked to cultural, religious or spiritual beliefs to different degrees and there may be conflicting views about this within a family system or wider support network. Therefore, support provided by faith and community organisations play a crucial role in assisting older people with their psychosocial needs.

Healthcare professionals at the specialist level should consider the following recommendations alongside an intersectional approach (see page 16) and the social graces model (Burnham, 2012) when developing a formulation with an older person with cancer (developed from Laidlaw, 2015):

- How the person's multiple identities might shape their cohort beliefs; role investments and changes in roles/ concerns about loved ones; intergenerational linkages; beliefs about ageing; physical health and knowledge and beliefs about death and dying.
- Healthcare professionals at the specialist level should seek to understand the person's sociocultural context (see What do older people know about cancer section) and what communities of people they feel a part of and could seek support from in thinking about possibilities for strengthening resources alongside or in preparation for therapeutic interventions.
- People with cognitive impairment, physical or neurological comorbidities may require different session lengths to the standard 50 minute "therapeutic hour", greater use of in session practice, and session summaries (including written or audio) and opportunities to consider key points to share with family and carers during or after appointments. Audio recording a summary in the session for the family to listen to together (with consent) can be helpful.

SECTION 3. Working in partnership with families and carers

This section looks at how services can work in partnership with families and caregivers of older people living with and beyond cancer to improve their experiences. This section is likely to be relevant to healthcare professionals providing support at all three levels.

In the UK, it is estimated that nearly 1.5 million people care for someone with cancer (Macmillan Cancer Support, 2016), and it is thought that almost every family across the globe is impacted by cancer in some way (WHO, 2024). Not only does cancer have a significant psychological impact on patients, but the majority of carers experience anxiety and depression (67% and 42% respectively; Cardy, 2006). Despite evidence supporting that carers may benefit from receiving psychosocial interventions (e.g., psychoeducation, skills training and counselling; Molassiotis & Wang, 2022), less than a quarter receive any psychological support at all (Cardy, 2006).

For cancer services to be safe and effective, good, trauma-informed psychological care must be offered to people with cancer and their families and carers (Cavell & Curtis, 2024; NICE, 2004). The health outcomes of older people with cancer and their families and carers are interdependent, meaning that the quality of care received can impact the physical and psychological functioning and wellbeing of both parties (Bedaso et al., 2022; Chua et al., 2020). As such, it is important to understand and respond to the support needs of those affected by cancer, both directly and indirectly.

Importantly, when friends or family take on the role of caring for a loved one with cancer, they may not identify with the term ‘carer’ (Macmillan Cancer Support, 2015c). Equally, not all families will be able and/or willing to provide informal care to their loved ones. Moreover, carers may be older adults themselves, and thus more likely to be passive recipients of care too. As such, healthcare professionals must be skilled in assessing and recognising when family members and friends are taking on caregiving responsibilities.

The effects of caring for people with cancer are well documented, with stress and competing demands impacting quality of life, physical health and mental well-being (Molassiotis & Wang, 2022). Alongside coping with emotional distress (e.g., grief, loss), family members and carers often have several practical responsibilities (e.g., household upkeep, transportation to appointments, treatment management, end-of-life planning; Nemati et al., 2017), which can quickly deplete physical and financial resources.

Despite families and carers playing a pivotal role in cancer care, there is a lack of research that investigates the experiences and preferences for psychosocial support needs within UK populations (see Price et al., 2024). The available evidence

suggests family members and carers value holistic assessments of their needs across the following six domains (Jack et al., 2016):

- **Communication and being cared for**

People with cancer and carers valued when staff were open, communicative and sensitive. They also felt supported when staff had an in-depth and holistic understanding of the needs of the person with cancer. Carers valued emotional support and understanding from staff that felt genuine. Carers also noted training needs for staff in communicating with older people with multi-morbidity needs like dementia. Carers reported patronising tones, not speaking directly to the patient, and expecting the carer to understand medical terminology and 'translate' back to the person with cancer.

- **Information**

People with cancer and carers value when staff were noticeably knowledgeable about cancer care, and shared insight pertaining to end of life preparation, pain management, at home support provisions and signposting to existing support and centralised support for long terms conditions. They also valued being given information about symptom awareness to look out for recurrence and treatment complications, as well as how to safely support with personal care in a dignified way. When carers were given appropriate information for how to care well, their anxiety reduced and their confidence increased (Nemati et al., 2017).

- **Involvement**

Carers report anxiety and low confidence in their caring abilities and valued being involved in the clinical side of care. For instance, they found nurses teaching them moving and handling skills like sheet manoeuvres to be beneficial when supporting a person with cancer at home.

- **Peer support**

Improvements in wellbeing were noted by those that attended peer support sessions, however, barriers to access included finding time available outside of caring responsibilities. Bereaved carers found helping others to have a positive impact on their wellbeing and coping abilities by helping them to make meaning of their experiences with grief and loss.

- **Integration**

The carers for people with cancer and other comorbidities expressed a lack of cohesion and understanding between different services as to how cancer interplays with other long-term conditions like dementia. This led to a lack of awareness of how cancer treatment impacts medication for other LTC and how this can alter the mood, cognition and personality of people with cancer, which caused further distress to carers.

- **Adapting services to suit multi-morbidity needs**

Where services do not adapt to suit needs of people with cancer with LTC/multi-morbidities, carers report this puts undue pressure on carers and people with cancer.

These six domains are consistent with the experiences of stakeholders who contributed to the development of this guidance, particularly people with lived experience of cancer as a carer or family member, and those working within older adult services and primary care. Stakeholders reported several challenges in relation to multimorbidity and communication about how other aspects of ageing and health might intersect with cancer and cancer treatment. For instance, stakeholders reported not knowing who to approach to make sense of all the information, who was overseeing the co-ordination of care across services, and lengthy delays between communication in different parts of the system impacting on patient experience.

> “There is a need for instant communication between physical health services and cancer services. We couldn't get answers from NHS consultants regarding how cancer treatment impacts treatments for other pre-existing long-term conditions and vice versa”.
>
> - Quote from Older Person with Cancer

> “When my partner became really poorly, the staff fast-tracked us straight to the oncology ward so that we could avoid a long wait in A&E. Things like that make a difficult job do-able".
>
> - Quote from Older Person Caring for their Partner with Cancer

Recommendations

Effectively supporting carers as well as older people with cancer means specialist cancer services should:

74. Be able to recognise when family and friends are taking on informal caregiving roles and responsibilities and assess their needs in response.
75. Be able to signpost to the most appropriate local service including peer support for carers (including local authority carers’ services, NHS Talking Therapies for Anxiety and Depression, local psycho-oncology services that accept referrals for carers, or third sector VCSE organisations, such as Carers UK.

76. Support carers to be involved in conversations about care needs and wishes (see section 2.4).
77. Be prepared to signpost older people and family and carers to advice about anxiety provoking and/or emotive topics such as carer's assessments, driving and dementia, lasting power of attorney and advance directives.
78. Support carers with improved health literacy, access to information and support in order reduce anxiety at the unknown and increase feelings of control and empowerment (see section 2.2 on health literacy).
79. Consider how services include and communicate with carers in the patient pathway for older people (see section 2.3 on communication) bearing in mind the carer may themselves be an older person, a person with cognitive, sensory or physical co-morbidities, and may need signposting to GP services and organisations such as Age UK.
    a. If cognitive impairment in an older person's family member or carer is suspected, healthcare professionals should offer to refer the person to a specialist dementia diagnostic service for an assessment as per NICE guidelines (2018b).
80. Provide clear information to carers about who to approach regarding various aspects of care, such as potential treatment side effects and concerns about treatment interacting with or exacerbating existing health conditions.
81. Be aware that older people from diverse communities may wish for a friend rather than a relative to accompany them to medical or therapy appointments, be involved in practising psychological skills outside of therapy or to be present for sessions or appointments focusing on end-of-life care wishes. There may be a sense of chosen rather than biological family or a community associated with an aspect of one's identity.
82. Work in partnership with local cancer information and support centres to plan the delivery of the above.

SECTION 4. Training, education and support for staff

This section makes recommendations to facilitate the delivery of compassionate care for older people with cancer and to operationalise the recommendations in the preceding sections. It is most relevant for all commissioners of health education; service leads and managers.

Trauma is a significant and pervasive public health issue (Magruder et al., 2017) with well-documented links to poor health outcomes (Wamser et al., 2023). For older people, it is estimated that between 50% and 90% have experienced at least one traumatic event in their lifetime (Pless Kaiser et al., 2019). For many older people who have experienced adverse life events, a cancer diagnosis and/or treatment not only threatens their physical health but also their psychological safety, coping strategies and sense of control, as historical trauma has the potential to re-emerge and be exacerbated by services (Dow, 2022).

The recently published West Midlands Trauma Informed Workforce Learning and Development Framework (Cavell & Curtis, 2024) highlights the responsibility of health and social care professionals to safeguard against the traumatisation and re-traumatisation of people using services and makes detailed recommendations for delivering compassionate care, for example using language that promotes dignity and understanding, and thus reduces anger and shame. Healthcare professionals are more able to provide compassionate care when their own support needs are met (they are well supported and shown compassion from colleagues and managers), they have access to regular clinical supervision or reflective practice, and unchecked systemic pressures do not contribute to burnout or stress (Point of Care Foundation, 2017).

To implement the recommendations from the preceding sections, healthcare professionals across all three levels of psychosocial support will benefit from further training, education and support.

Recommendations

83. All healthcare staff working with older people affected by cancer should complete health inequalities and diversity training such as CMCA 123 Approach.
84. All healthcare staff across with older people affected by cancer should complete communication skills training such as Sage and Thyme.
85. Inclusion of age as an Equality, Diversity and Inclusion factor (alongside the other EDI factors) and lifespan perspectives on cancer and ageing into training produced or commissioned by the Cancer Alliance Academy.
86. All healthcare staff should have access to dementia awareness information and training informed by The Dementia Training Standards Framework (Skills for Health, Health Education England, and Skills for Care, 2018).

87. Services to make use of an audit tool to reflect on progress towards offering age-inclusive and age-responsive services (a template that could be amended to suit local plans is provided in Appendix 5).
88. Services to periodically monitor and track the data gathered by the audit tool to evaluate the impact of the guidance and feedback to the Cancer Alliance/ICB Cancer Board as appropriate.
89. Cancer services to work in partnership with experts in older people's mental health, cognition and learning disabilities services to develop local policies for best practice in best interests meetings.
90. The recruitment of 'Older People's Cancer Champions' within each cancer service, clinical health psychology or specialist psycho-oncology service to work alongside the Cancer Alliance to implement the recommendations in this guidance, build awareness of need, identify service-specific gaps and consider evaluation in relation to progress towards reducing health inequalities for older people.
    a. NHS Talking Therapies and LTC services to work towards appointing older people champions in line with the Positive Practice Guidance recommendations (BABCP, 2024).
91. The Cancer Alliance to develop peer support sessions for 'Older People's cancer champions' to share learning and discuss progress towards positive practice changes, with access to a specialist in older adult psychology for expert advice and supervision.
92. Clinical supervisors at the specialist level should aim to develop a trusting relationship with a clinical supervisee to enable self-reflection and foster an environment to explore and challenge assumptions about age (and all EDI factors).
93. Clinical supervision should offer the opportunity to consider how intersectionality and the older person's and healthcare professionals' beliefs about age, and death/dying are important in clinical practice with older people with cancer.
94. Healthcare professionals working at the specialist level could make use of resources to support critical thinking and increasing awareness of assumptions about ageing within their own practice and that of supervisees (such as Burnham, 2012; Laidlaw et al., 2016).
95. Healthcare professionals working at the specialist level should use theories of identity such as the updated social graces model (Burnham, 2012) to explore the aspects of identity that older people bring to cancer care including their sex, sexuality, gender expression and appearance, disability, race, ethnicity and culture, geography and economics within the scope of their roles and support their supervisees to develop an understanding of intersecting identities within clinical supervision.
96. Psycho-oncology and clinical health psychology leads to establish links with local older adult mental health and memory assessment services to

collaborate and consult on complex clinical cases where older people receiving cancer-treatment with cognitive side effects may be referred for screening for emerging cognitive impairment.

97. Where psycho-oncology services provide training and education to psychological professions courses (e.g., Doctorate in Clinical Psychology, Clinical Associate Psychologist Apprenticeship and training courses for NHS Talking Therapies staff), such training promotes age-sensitive care as part of the curriculum, that is co-produced and/or co-delivered with experts by experience.
98. The Cancer Alliance to collaborate with colleagues at the national level to formalise links between local Cancer Alliances and the NHSE programmes in Mental Health, Living with and Beyond Cancer and the Cancer Workforce, the British Psychological Society Group of Trainers in Clinical Psychology and the Faculties for the Psychology of Older People and Oncology and Palliative Care to promote age-sensitive care amongst the trainee psychologist workforce.
99. Clinical supervision and/or reflective practice facilitators to provide an education component during case discussion, to include consideration of the needs of older people and how distress may present for the current cohort of older adults.
100. Practitioners at the specialist level should access CPD in relation to older people where this is a gap in post-qualification knowledge and clinical experience.
    a. Talking Therapies staff are expected to consult and adhere to the Positive Practice Guide for Older People (BABCP, 2024).
    b. Trainee clinical psychologists are also expected to follow BABCP clinical competencies.

Conclusion

This guidance outlines the key actions that services and healthcare professionals can take to address the health inequalities experienced by older people living with and beyond cancer. The recommendations focus on identifying and removing the barriers that might prevent older people, their families, and carers from accessing appropriate psychological support at the right time. Greater knowledge of the varied needs of older people amongst the workforce will improve the delivery of person-centred, psychological and trauma-informed care. For a complete list of recommendations see Appendix 1.

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Appendices

Appendix 1. Full list of recommendations, separated into older adult specific recommendations, and person-centred, all-age recommendations applicable to all client groups.

Older adult specific recommendations:

1. Services should avoid using “opt-in” models which exclude older people with low literacy, English as a second language, cognitive difficulties and digital deprivation.
2. Healthcare professionals should consider how an older person will get to appointments if they are not going to be seen at home and be aware of the financial impact of travel; signposting to information and support in relation to financial distress such as Citizens Advice Bureau, Age UK and Macmillan.
3. Be flexible and offer appointments at an appropriate time of day, which may mean excluding early morning or late afternoon appointments to support older people with chronic pain, cognitive impairment and/or other disabilities to attend at their optimal time to benefit most from therapeutic interventions (for instance some people with dementia may experience a worsening of symptoms late afternoon).
4. Avoid appointments at peak travel hours so that people can benefit from discounted or free public transport such as senior railcards and older people’s bus passes.
5. When considering a referral for psychosocial support at the enhanced or specialist level, be aware that older people may have different understandings of what psychological therapy involves. It is important to offer opportunities to ask questions and signpost to resources for more information.
6. Local psychosocial service leaflets and websites should be made accessible to older people and be offered in print as well as digitally.
7. Older people may talk about their feelings of anxiety and depression differently and use different language to working age adults. They may speak in terms of physical symptoms such as “nerves”, bodily ailments or withdrawal from activities or social relationships, which could indicate anxiety, low motivation or hopelessness.
8. Healthcare professionals at the universal level should focus their attention on providing key information in a range of formats across the following domains:
    a. **Age-related risk of cancer and complications:** Health literacy information regarding risks, signs and symptoms of disease progression or complications that might arise during treatment and what to do/when advice given to reduce anxiety and support future planning should be provided to older people as a preventative measure.
    b. **Treatment myths:** More case studies could be used in infographics/leaflets disseminated within healthcare services, and

increased provision of older adults facilitating peer support or Living with and Beyond Cancer workshops and wellbeing events within the community to dispel some of the preconceived misconceptions about cancer treatments for older people.

c. **Information sharing that encourages participation in care**: Holistic needs assessments and co-produced support plans are required to inform and promote information sharing between clinicians and older people with cancer about their diagnosis, prognosis, treatment, co-morbidities, at-home care, and survivorship. Making use of resources (see Ariadne Labs & The Conversation Project, 2021) can empower older people and their families and carers in preparing for and getting the most out of appointments as active participants of rather than passive recipients of healthcare.
d. **Further specialist support:** Better signposting to and awareness of specialist psychosocial support services amongst healthcare staff, with an emphasis on protecting independence, and local community support, providing physical leaflets and telephone numbers where someone is unlikely to be able to access digital resources such as the Cancer Care map.

9. Develop lunch and learn sessions for staff to share case studies and create learning opportunities around the health literacy needs of older people.
10. Ensure services promote resources in line with the key focus areas, in formats that suit the older people using those services.
11. Work with older people to co-identify important information and reduce to key points and reinforce (what does the older person in front of you want to know and how do they want to learn this?).
12. Check the older person, family and carers' understanding with teach-back/role play with questions. Asking "would you like to tell me what you've understood from what I've just said?" is more informative than asking "do you understand?".
13. Encourage older people to use resources to help support conversations in healthcare appointments such as 'What Matters to Me: A Workbook for People with Serious Illness' (Ariadne Labs & The Conversation Project, 2021).
14. The current cohort of older people may need to be invited to talk about their experience holistically, as some people may hold beliefs about "wasting professionals' time."
15. Consider each appointment an opportunity to assess understanding of care plans and provide education to the older person, family or carers where appropriate.
16. Reassess concerns and support needs frequently throughout treatment or during each cancer care review (recognising that the situation may have become more complex or anxiety-provoking with co-morbidities more likely to

be identified/treated by another healthcare team during cancer treatment than in younger people).

17. Avoid reliance on ‘opt-in’ methods of managing referrals; these are likely to deny access to the most vulnerable in society including older people, and in particular older people with English as an additional language (or no English) and people with cognitive impairment and learning disabilities.
18. Use multiple systems (to include physical letters or phone calls) to communicate with older people about appointments. Digital systems can be helpful for older people using assistive technologies but disadvantage people without access or ability and people who may need the support of carers to make sense of information.
19. Establish trust and a rapport by speaking to older people with compassion, dignity and respect, identifying preferred terms from the offset.
20. Practice compassion within interactions (speak slowly and plainly, be patient and aware of differences in processing times for older people, especially those with learning disabilities or English as a second language).
21. Co-production with the older person and their carer/family members before an End of Treatment Summary (EOTS) is sent to understand the usefulness of this document and reduce the time taken in subsequent appointments with healthcare professionals outside of cancer trying to make sense of the content of EOTS (‘de-coding’).
22. Consider an older person's life holistically. Areas of focus in a plan should be on housing suitability, monitoring and addressing changing needs, capabilities and capacity (to include caring for others/pets, physical mobility, cognition, frailty), building and maintaining support networks (carer assessments, support needs of family members), money management, legal arrangements (in relation to driving licence, wills, power of attorney, resuscitation wishes) and (if applicable) end of life planning.
23. Include relevant contingency planning and education on potential sudden changes/crises (illness or death of carer, delirium, or unexpected hospital admission during cancer treatment) to empower older people and family and carers to feel more knowledgeable about what to do and how to cope with uncertainty and change if a challenge arises.
24. Offer repeated opportunities for older people to express their religious or spiritual needs during their final weeks, and these preferences should be recorded on case notes and respected by all staff.
25. Older people may want to consider sharing their experiences and beliefs with religious or spiritual leaders during their final weeks in particular.
26. Training in how to offer a discussion of the sexual health and intimacy needs of older people with cancer should be incorporated into existing training for healthcare professionals working at the enhanced and specialist level.
27. The complexity of the role and context for an older people with cancer who is also a caregiver should form part of any needs assessments that might take

place during the cancer journey such as during health needs assessments, cancer care reviews, primary care mental health or psycho-oncology assessments.

    a. Healthcare professionals should work collaboratively with an older person with cancer and caregiving responsibilities to identify ways to support them in continuing or reducing (dependant on need and wishes) their caregiving responsibilities alongside their own cancer care and treatment.

28. Older people with cancer who are also caregivers should be signposted to appropriate local and regional support services which may include the local authority carers support service as well as organisations such as Carers UK, Age UK, Alzheimer's Society and Dementia UK.
29. Consider using audit tools to adapt areas into dementia-friendly environments to reduce the potential for additional anxiety and confusion caused by attending hospital or outpatient clinics. For example, Environments for Ageing and Dementia Design Assessment Tool (Dementia Services Development Centre, 2022) and Dementia Friendly Environment Checklist (Alzheimer's Society, 2024). These make suggestions of a practical nature, such as ensuring regular resting places along corridors in treatment centres or outpatient clinicals areas.
30. Healthcare professionals can signpost to and find support and information in resources such as the Macmillan and Dementia UK guides to cancer and dementia (for people with cancer and for carers; 2017b, 2020b)
31. All healthcare staff should have access to dementia awareness information and training informed by The Dementia Training Standards Framework (Skills for Health, Health Education England, and Skills for Care, 2018).
32. When assessing how an older person has been coping with activities of daily living prior to cancer diagnosis, healthcare professionals should consider inviting family and carers to contribute to discussions.
33. Healthcare professionals should invite older people and family and carers to discuss their concerns about cancer in relation to existing cognitive difficulties and work in partnership with older adult mental health or learning disability teams to plan for how to monitor the impact of treatment on symptoms so that care can be reviewed as necessary.
34. Healthcare professionals should encourage older people and families and carers to make contingency plans that will support a person-centred approach to care for someone with mental health, learning disabilities or cognitive impairment for instance, prepare a bag with important items of comfort and familiarity for unplanned admissions to hospital, complete the "This is Me" booklet and consider making plans for the future such as wills and power of attorney (See Conversations about care needs, wishes, and managing unexpected situations section).

35. Acute services should review the information provided to older people on admission to hospital for cancer treatment or the management of cancer-related complications and co-produce resource packs with key information for the duration of the stay such as standard routines on the ward, telephone numbers for family to call and who to seek support from.
36. For healthcare professionals working with older people with cancer and learning disability or cognitive impairment there may be specific considerations in respect of consent to treatment and capacity (British Psychological Society, 2019). Adjustments can be made to clinical practice to attempt to enhance capacity such as longer and additional appointments in which the healthcare professionals:
    a. Use simple, everyday words to explain the necessary information and ensure the older person/the person with lasting power of attorney for health and welfare understands, paraphrasing where necessary.
    b. Offer information in shorter, more digestible and easier to follow chunks.
    c. Provide short written information in the first language of the patient/the person with lasting power of attorney for health and welfare if literate.
    d. Use symbols or pictures to represent the key areas where literacy is an issue.
    e. Consider a supportive third party who can reinforce necessary learning where appropriate.
    f. Consider advice or input from a speech and language therapist for instance regarding assistive technologies that may support these conversations.
    g. Allow flexibility regarding scheduling and goals of care and prepare for shortened or unpredictable duration or frequency of therapy sessions.
37. Healthcare professionals at the universal level can support older people with cancer and families to complete health passports such as “This is Me;” a tool to communicate essential information about the person with cognitive impairment if they are unable to share it directly (Alzheimer’s Society, 2021).
38. Audit the use of holistic needs assessments at key intervals through the older person’s journey with cancer services (National Institute for Health and Care Excellence [NICE], 2004).
39. WMCA to lead stakeholders through a process of agreeing system-wide best practice in relation to:
    a. which settings and which professionals are best equipped to discuss the potential for post treatment pain (and late effects).
    b. developing local knowledge of appropriate resources and sources of support for fatigue, pain and sleep difficulties, which are the most common problems reported by older people on the Quality of Life survey (NHS, 2024) in the West Midlands (60-69 years; 85%, 92.6%,

73.2%; 70-79 years; 85.7%, 94.2%, 76.5%; 80+ years; 79%, 92%, 74.1% respectively).

40. Healthcare professionals at the universal level should be aware of the physical comfort and pain levels of the older person in an appointment and give permission for moving around or standing (for example to manage symptoms of chronic pain).
41. Healthcare professionals should strive to include all relevant health information within referrals to reduce duplication for older people (e.g., sharing the results of samples taken by one part of the healthcare system such as urgent care, with the GP and continence team to minimise physical discomfort for older people living with frailty in being asked to provide multiple samples.
42. Older people's cancer champions to support work to embed frailty assessments in clinical pathways for older people coming into hospital for or during cancer treatment
    a. Consider the recruitment of older people's Experts by Experience to work alongside older people's cancer champions, and the involvement of EDI leads/teams in working to embed, develop and support people in these roles within services.
43. Healthcare professionals working at the universal level should be able offer basic safety planning to include:
    a. contact information for the local mental health crisis team.
    b. how to access specialist advice from or escalate concerns to local primary or secondary care services for older people and social care/ safeguarding leads.
    c. informing all prescribers in the person's care plan across primary, secondary, and tertiary care settings.
44. Healthcare professionals working at the enhanced level should have access to training on appropriate adaptations to assessments of risk in older people with cancer as part of level two training programmes.
    a. Healthcare professionals at the specialist level should have access to training on appropriate adaptations to assessments of risk in older people with cancer (as part of LTC top-up training for staff in Talking Therapies for anxiety and depression and/or clinical psychology training programmes), with knowledge of local support pathways and resources for signposting within both the NHS and local voluntary and community organisations.
    b. Further advice is available from International Association for Suicide Prevention (2024) and Zero Suicide Alliance (2024).
    c. Trust-level considerations should be made regarding implementing suicide awareness and prevention education as part of statutory and mandatory training for all staff.
    d. Be able to identify signs of domestic abuse and neglect in older people with cancer, and signpost them to appropriate local services.

45. Be prepared to signpost older people and family and carers to advice about anxiety provoking and/or emotive topics such as carer's assessments, driving and dementia, lasting power of attorney and advance directives.
46. Consider how services include and communicate with carers in the patient pathway for older people (see section 2.3 on communication) bearing in mind the carer may themselves be an older person, a person with cognitive, sensory or physical co-morbidities, and may need signposting to GP services and organisations such as Age UK.
    a. If cognitive impairment in an older person's family member or carer is suspected, healthcare professionals should offer to refer the person to a specialist dementia diagnostic service for an assessment as per NICE guidelines (2018b).
47. Be aware that older people from diverse communities may wish for a friend rather than a relative to accompany them to medical or therapy appointments, be involved in practising psychological skills outside of therapy or to be present for sessions or appointments focusing on end-of-life care wishes. There may be a sense of chosen rather than biological family or a community associated with an aspect of one's identity.
48. Work in partnership with local cancer information and support centres to plan the delivery of the above.
49. All healthcare staff working with older people affected by cancer should complete health inequalities and diversity training such as CMCA 123 Approach.
50. All healthcare staff across with older people affected by cancer should complete communication skills training such as Sage and Thyme.
51. Inclusion of age as an Equality, Diversity and Inclusion factor (alongside the other EDI factors) and lifespan perspectives on cancer and ageing into training produced or commissioned by the Cancer Alliance Academy.
52. Services to make use of an audit tool to reflect on progress towards offering age-inclusive and age-responsive services (a template that could be amended to suit local plans is provided in Appendix 5).
53. Services to periodically monitor and track the data gathered by the audit tool to evaluate the impact of the guidance and feedback to the Cancer Alliance/ICB Cancer Board as appropriate.
54. Cancer services to work in partnership with experts in older people's mental health, cognition and learning disabilities services to develop local policies for best practice in best interests meetings.
55. The recruitment of 'Older People's Cancer Champions' within each cancer service, clinical health psychology or specialist psycho-oncology service to work alongside the Cancer Alliance to implement the recommendations in this guidance, build awareness of need, identify service-specific gaps and consider evaluation in relation to progress towards reducing health inequalities for older people.

    a. NHS Talking Therapies and LTC services to work towards appointing older people champions in line with the Positive Practice Guidance recommendations (BABCP, 2024).

56. The Cancer Alliance to develop peer support sessions for ‘Older People’s cancer champions’ to share learning and discuss progress towards positive practice changes, with access to a specialist in older adult psychology for expert advice and supervision.
57. Clinical supervisors at the specialist level should aim to develop a trusting relationship with a clinical supervisee to enable self-reflection and foster an environment to explore and challenge assumptions about age (and all EDI factors).
58. Clinical supervision should offer the opportunity to consider how intersectionality and the older person’s and healthcare professionals’ beliefs about age, and death/dying are important in clinical practice with older people with cancer.
59. Healthcare professionals working at the specialist level could make use of resources to support critical thinking and increasing awareness of assumptions about ageing within their own practice and that of supervisees (such as Burnham, 2012; Laidlaw et al., 2016).
60. Healthcare professionals working at the specialist level should use theories of identity such as the updated social graces model (Burnham, 2012) to explore the aspects of identity that older people bring to cancer care including their sex, sexuality, gender expression and appearance, disability, race, ethnicity and culture, geography and economics within the scope of their roles and support their supervisees to develop an understanding of intersecting identities within clinical supervision.
61. Psycho-oncology and clinical health psychology leads to establish links with local older adult mental health and memory assessment services to collaborate and consult on complex clinical cases where older people receiving cancer-treatment with cognitive side effects may be referred for screening for emerging cognitive impairment.
62. Where psycho-oncology services provide training and education to psychological professions courses (e.g., Doctorate in Clinical Psychology, Clinical Associate Psychologist Apprenticeship and training courses for NHS Talking Therapies staff), such training promotes age-sensitive care as part of the curriculum, that is co-produced and/or co-delivered with experts by experience.
63. The Cancer Alliance to collaborate with colleagues at the national level to formalise links between local Cancer Alliances and the NHSE programmes in Mental Health, Living with and Beyond Cancer and the Cancer Workforce, the British Psychological Society Group of Trainers in Clinical Psychology and the Faculties for the Psychology of Older People and Oncology and Palliative

Care to promote age-sensitive care amongst the trainee psychologist workforce.

64. Clinical supervision and/or reflective practice facilitators to provide an education component during case discussion, to include consideration of the needs of older people and how distress may present for the current cohort of older adults.
65. Practitioners at the specialist level should access CPD in relation to older people where this is a gap in post-qualification knowledge and clinical experience.
    a. Talking Therapies staff are expected to consult and adhere to the Positive Practice Guide for Older People (BABCP, 2024).
    b. Trainee clinical psychologists are also expected to follow BABCP clinical competencies.

Person-centred, all-age recommendations:

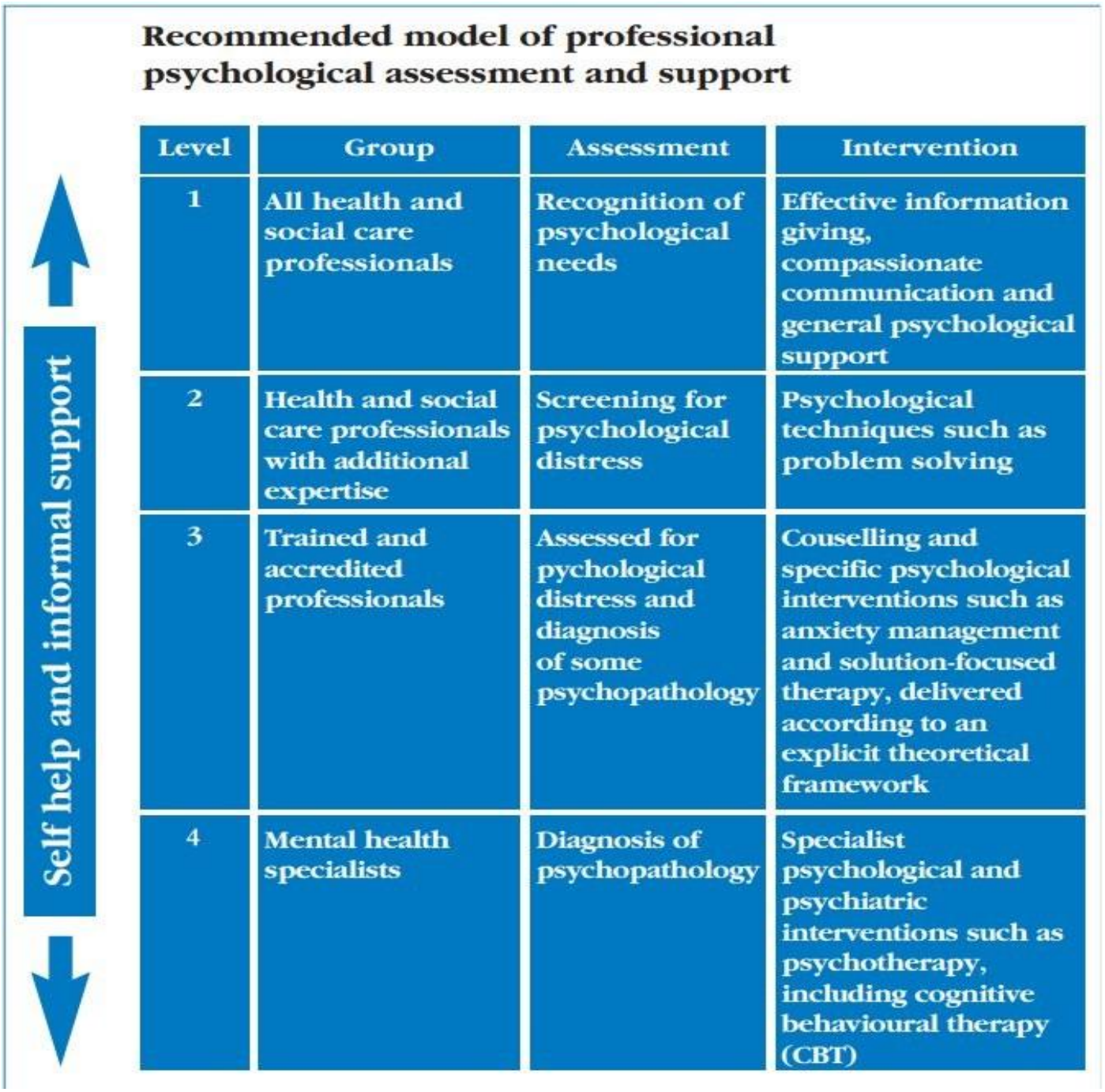
66. Services should work in partnership with Equality Leads, Patient Experience teams, local communities and organisations representing service users who are under-represented in support services to find suitable models of service that do not contribute to the Core20PLUS5 health inequalities.
67. Services should collect race, sex, disability (including learning disabilities/mental health conditions), sexual identity and gender diversity characteristics within the cancer registry to improve understanding of the needs of the community.
68. Seek to promote accessible services using simple language in letters and on signs, clear signage and accessible routes into clinical areas.
69. Send photographs of the entrance to the building and any complex internal routes with first appointment letters.
70. Consider parking, affordability of travel/public transport, mobility and sensory friendly environments.
71. Provide clear and accessible written and verbal communication, on topics such as accessing support in the community, health care at home, and the biological, psychological and social impacts of having cancer.
72. Consider a range of factors including intersectionality, neurodivergence, cognitive and sensory impairments, digital exclusion and poverty and cultural differences.
73. Documentation should invite people to bring hearing aids or reading glasses to support communication and ability to fully engage with information.
74. Explain who the healthcare professionals present are and the purpose of appointments/telephone calls (there may be a need to do this more than once during a conversation).

75. Assess and address communication needs throughout interactions, ask if patients can hear/see information being shared on screens, and offer frequent opportunities to clarify/check understanding etc.
76. Ask open ended questions but be prepared to use yes/no and multiple-choice questions to support someone with cognitive impairment.
77. Direct body language and turn towards patients when speaking.
78. Provide written and verbal communications, ask for preferences, and consider the involvement of family and carers during or at the end of appointments.
79. Be culturally sensitive and aware of differing needs.
80. When consent has been given, include family members and carers in discussions.
81. When broaching sensitive topics, take a universal approach “Many people experience...”
82. The development of co-produced standardised EOTS templates that are specific to the West Midlands population.
83. Ensure care planning is person-led, and where appropriate include family members, carers and advocates.
84. Ensure care plans are co-produced with a practitioner that is well known and trusted by the person and their wider network.
85. Seek and include input from practitioners with knowledge and awareness of local resources.
86. Provide ‘packing lists’ to support people who may need to be away from home for treatment to know what to bring with them to increase their comfort levels and provide familiarity and reassurance at a vulnerable time.
87. Foster an environment where discussing, preparing and planning for death is normalised, as honest and open conversations about dying can facilitate dying ‘well.’
88. Encourage re-framing of perspectives on planning for death, moving from ideas of defeatism to regaining control and being able to focus on remaining life.
89. If cancer is palliative, the opportunity to discuss plans, preferences and the emotional impact of end of treatment, death and dying should be created.
90. The psychological impact of difficulties related to cancer, intimate relationships, sexual health and intimacy should be included in holistic needs assessments and onward referral to psychological support services at the enhanced or specialist level made accordingly.
    a. Signposting to organisations specialising in relationship counselling such as Relate.
91. Where areas of the West Midlands are served by dedicated psychosexual services these should be identified for onward referral where appropriate.
92. Healthcare professionals should signpost to sources of emotional support in relation to concerns about how cognition might be impacted by cancer treatment and how dementia might impact on decisions about treatment such

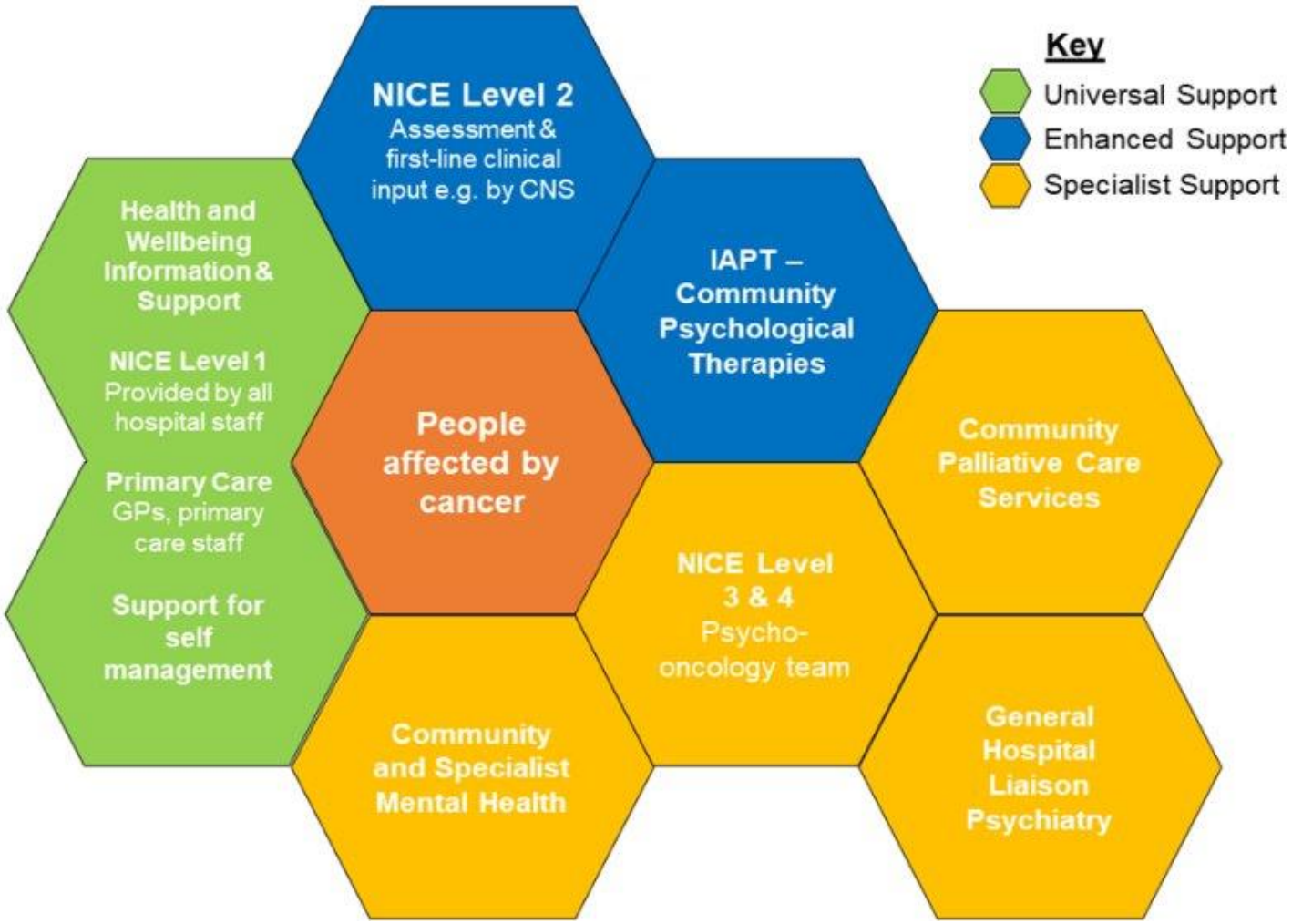
as Macmillan's cancer and dementia booklet (Macmillan Cancer Support, 2020a), and guide for carers (Macmillan Cancer Support, 2017b).

93. Consider utilising local clinical ethics committees, where available, for support where best interest decisions are complex and/or contested.
94. Further recommendations to support people with cancer with sleep and fatigue difficulties are within the recommendations of WMCA Mapping Report (Gürpınar et al., 2023).
95. Healthcare professionals at the enhanced and specialist levels should be provided with training on how to talk about the more emotive/sensitive potential health effects of cancer and side effects of treatment within level two training (specifically for the cancer workforce), long term conditions top up training (for the Talking Therapies workforce) and in an induction that meets the standards of the British Psychosocial Oncology Society and the Division of Clinical Psychology's Faculty for Oncology and Palliative Care (for practitioner psychologists).
96. Staff should be able to recognise when family and friends are taking on informal caregiving roles and responsibilities and assess their needs in response.
97. Staff should be able to signpost to the most appropriate local service including peer support for carers (including local authority carers' services, NHS Talking Therapies for Anxiety and Depression, local psycho-oncology services that accept referrals for carers, or third sector VCSE organisations, such as Carers UK.
98. Staff should seek to support carers to be involved in conversations about care needs and wishes (see section 2.4).
99. Staff should seek to support carers with improved health literacy, access to information and support in order reduce anxiety at the unknown and increase feelings of control and empowerment (see section 2.2 on health literacy).
100. Provide clear information to carers about who to approach regarding various aspects of care, such as potential treatment side effects and concerns about treatment interacting with or exacerbating existing health conditions.

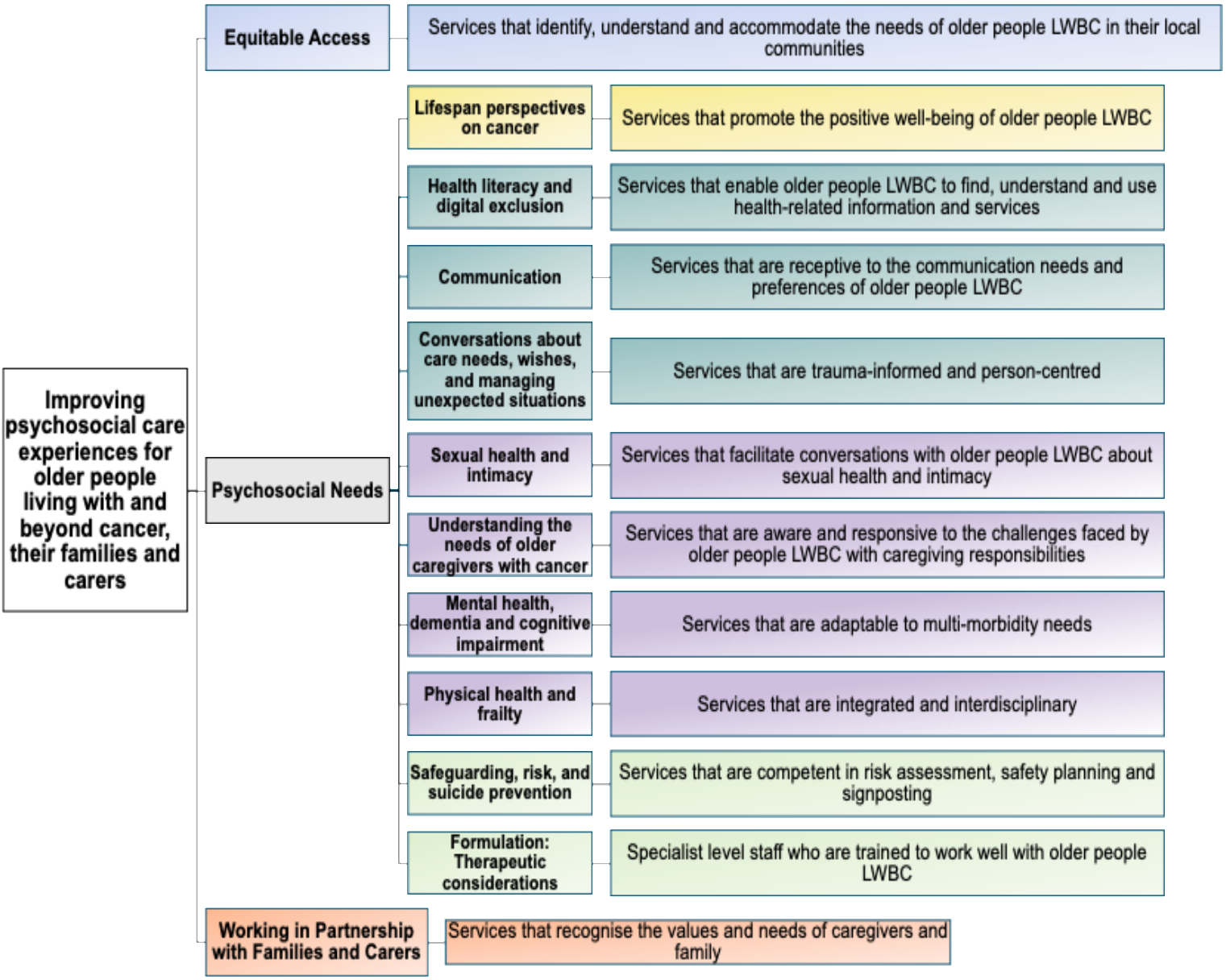
Appendix 2. The four levels of psychosocial support (NICE 2004) and three levels of psychosocial support recommended by the London Transforming Cancer Services Team in 2020.



Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for pychological distress and diagnosis of some psychopathology	Couselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)


Key
Universal Support
Enhanced Support
Specialist Support
NICE Level 2
Assessment & first-line clinical input e.g. by CNS
Health and Wellbeing Information & Support
NICE Level 1
Provided by all hospital staff
Primary Care
GPs, primary care staff
Support for self management
IAPT – Community Psychological Therapies
People affected by cancer
Community Palliative Care Services
NICE Level 3 & 4
Psycho-oncology team
Community and Specialist Mental Health
General Hospital Liaison Psychiatry

Appendix 3. Thematic map for the development of this guidance



Appendix 4. How to use the self-assessment audit tools

The self-assessment audit tools aim to support services in efforts to reduce identified avoidable differences in care quality and experiences that older people, their families, and carers experience in the cancer pathway.

Two tools, one for healthcare professionals and one for service users, have been developed in line with the guidance document; they are based on current literature, research, policy, and the lived experiences of older people, their families and carers. These reflective tools focus on the actions required by services in the West Midlands to address and tackle health inequalities faced by older people living with and beyond cancer. Services are encouraged to develop their own internal mechanisms to track and monitor data to evaluate the effectiveness of implementing this guidance.

Integrated Care Boards are encouraged to use data from these tools to identify and prioritise key focus points within their local service areas. If necessary, additional standards can be added. It is also recommended that each service designates staff older adult cancer champions to oversee and support the auditing process of both tools. These tools play a key role in ensuring consistent evaluation and improvement of practice for older people in collaboration with service users.

Appendix 5. Self-assessment audit tool: Providing psychosocial support for older people living with and beyond cancer (LWBC), their families, and carers.

This tool is designed to help healthcare professionals reflect on their competencies in providing equitable, safe, and effective psychosocial support across the core domains in the West Midlands Cancer Alliance Positive Practice Guide. Additional standards may be added. Please review each standard and rate your current practice as 'developing', 'good', or 'outstanding'.

Improvement Measure	Standard	Assessment Rating
1. Increasing Equitable Access to Psychosocial Support		
	Specialist psychosocial support services to audit demographic data (age) to determine parity of referrals with working age adults.	Developing/Good/Outstanding
	Specialist psychosocial support services to audit clinical outcomes and service user satisfaction for older people to determine parity with working age service users.	Developing/Good/Outstanding
	Services provide resources in multiple languages and formats, using simple language and imagery.	Developing/Good/Outstanding
	Services consider the use of audit tools to assess the need for adaptations to environments for older people, particularly those with dementia and other co-morbidities.	Developing/Good/Outstanding
	Services engage in co-production to action improvements to service design and delivery that better	Developing/Good/Outstanding

	accommodate community needs (e.g., opt-in alternatives, clearer signage and letters)	
	Services are aware of barriers to accessing care, such as transportation and digital exclusion, and work to address them through adaptations to practice like offering flexible appointments.	Developing/Good/Outstanding
	All staff have access to materials that support delivering adapted practice.	Developing/Good/Outstanding
	Staff are knowledgeable about health inequalities and have completed health inequalities training and CPD that covers working with diverse populations, including older people.	Developing/Good/Outstanding
	Staff working at the enhanced or specialist level have accessed training and CPD opportunities which included working well with older people (either therapeutically or in terms of providing supervision)	Developing/Good/Outstanding
2. Lifespan Perspectives on Cancer		
	Staff understand how attitudes, beliefs, and experiences of older people might influence their perspectives on illness and healthcare.	Developing/Good/Outstanding
	Staff are knowledgeable about the psychosocial impacts of cancer for older people, such as	Developing/Good/Outstanding

	loss of independence and changes in identity.	
	Staff undertake regular holistic needs assessments (HNAs) to inform care and support plans.	Developing/Good/Outstanding
	Staff are aware of the long-term consequences of cancer and cancer treatment and know where to refer older people for community-based support and specialist psychological support.	Developing/Good/Outstanding
	Staff promote positive mental well-being and recovery-oriented care for older people LWBC.	Developing/Good/Outstanding
2.1 Increasing Health Literacy and Reducing Digital Exclusion		
	Staff understand the impact of social determinants and long-term conditions on health literacy and digital exclusion, especially for older people with cancer, and adapt their practice to address this.	Developing/Good/Outstanding
	Staff recognise the importance of health literacy in gaining informed consent.	Developing/Good/Outstanding
	Staff have knowledge and understanding of how to use evidence-based health literacy tools, like teach-back and chunk and check techniques.	Developing/Good/Outstanding
	Staff have access to resources that support health literacy and	Developing/Good/Outstanding

	digital inclusion and adapt these for the specific needs and preferences of older people.	
2.2 Communication		
	Staff work within trauma-informed principles when communicating with older people (e.g. sensitivity and empowerment)	Developing/Good/Outstanding
	Staff assess and record the communication needs and preferences of older people and adapt their communication accordingly (e.g., through clear language, visual aids, and appropriate questioning).	Developing/Good/Outstanding
	Staff encourage older people to bring communication aids to appointments and check their understanding regularly.	Developing/Good/Outstanding
	Staff develop end-of-treatment summaries and personalised stratified follow-ups in collaboration with older people.	Developing/Good/Outstanding
2.3 Conversations About Care Needs, Wishes, and Managing Unexpected Situations		
	Staff offer opportunities for older people LWBC to discuss their care needs, future care planning, and how to manage unexpected situations, and encourage active participation in	Developing/Good/Outstanding

	decision-making and actions.	
	Staff ensure that all information provided to older people LWBC is clear and comprehensive, addressing what is known/not known about diagnosis, prognosis, treatment options, and future care.	Developing/Good/Outstanding
	When consent has been given, staff involve family members and caregivers in such discussions.	Developing/Good/Outstanding
2.4 Sexual Health and Intimacy		
	Staff are aware of the potential effects of cancer and cancer treatment on the sexual health and intimacy needs of older people LWBC.	Developing/Good/Outstanding
	Staff have the knowledge and training to address sensitive topics such as sexual health, intimacy, and related psychological impacts.	Developing/Good/Outstanding
	Staff are familiar with specialist psychosexual services and know how to refer older people to these services.	Developing/Good/Outstanding
2.5 Understanding the Needs of Older Caregivers with Cancer		
	Staff understand the unique challenges faced by older caregivers with cancer and have knowledge of tailored support services and resources.	Developing/Good/Outstanding

	Staff can identify psychological distress in older caregivers with cancer and know where to refer them for specialist psychosocial support.	Developing/Good/Outstanding
	Services accommodate the needs of older caregivers with cancer by offering flexible appointment scheduling and safe waiting areas.	Developing/Good/Outstanding
2.6 Mental Health, Dementia, and Cognitive Impairment		
	Staff recognise the challenges older people LWBC may face if they also have mental health difficulties, dementia, or cognitive impairment.	Developing/Good/Outstanding
	Staff can differentiate between psychological distress caused by cancer and that caused by mental health conditions, dementia, or cognitive changes.	Developing/Good/Outstanding
	Staff feel able to refer older people with cancer and mental health difficulties, dementia, or cognitive impairment to psychological support services.	Developing/Good/Outstanding
	Staff adapt communication and care plans to meet the needs of older people with dementia and cognitive impairment, co-producing personalised care	Developing/Good/Outstanding

	plans where appropriate.	
2.7 Physical Health and Frailty		
	Staff recognise the challenges older people with cancer may face if they also have other physical health difficulties and frailty.	Developing/Good/Outstanding
	Staff can differentiate between frailty and 'expected' age-related changes and understand how cancer and cancer treatment can affect physical health.	Developing/Good/Outstanding
	Staff are aware of key issues like fatigue, pain, and sleep difficulties in older people LWBC and address these through tailored care and support.	Developing/Good/Outstanding
	Staff have the knowledge and skills to adapt practice to support older people LWBC with frailty and other physical health challenges.	Developing/Good/Outstanding
2.8 Safeguarding, Risk, and Suicide Prevention		
	Staff are aware of the key risk factors for suicide and self-harm in older people LWBC, such as pain, isolation, and psychological distress.	Developing/Good/Outstanding
	Staff can identify signs of suicide risk and take appropriate actions, including safety planning and referring to crisis services.	Developing/Good/Outstanding
	Staff are trained in safeguarding and have	Developing/Good/Outstanding

	access to supervision and post-incident support.	
3. Working in Partnership with Families and Carers		
	Staff recognise the crucial role that families and carers play in the care of older people LWBC, and endeavour to work collaboratively with them.	Developing/Good/Outstanding
	Staff assess families' and carers' understanding of health-related information and care plans.	Developing/Good/Outstanding
	Staff are aware of the challenges faced by families and carers and can signpost or refer them to appropriate support services and resources.	Developing/Good/Outstanding
	Staff work in a trauma-informed and person-centred way with families and carers, assessing, identifying and addressing their psychosocial needs as part of care delivery.	Developing/Good/Outstanding

Self-Assessment Audit Tool for older people living with and beyond cancer (LWBC)

This tool helps you think about the quality of care and support you are receiving in the cancer pathway. It can be used to see where you may need more help or information. Once you fill it out, a staff member will talk about it with you.

1. Fair Access to Services

- Are your needs considered in your care? (e.g., race and ethnicity, religion, or other factors)
- Do you get information in the language or format you prefer?
- Can you get appointments at times that work for you?

2. Care and Support

- Do you get chances to talk about your cancer care?
- Do the staff explain things clearly and help you to understand information?
- Have they helped you to make a care plan?
- Do you feel well cared for and supported?

3. Mental Health

- Have you been offered support for stress, low mood, or any other new emotions?
- Do you know where to go for help with your mental health and well-being?

4. Physical Health

- Have you been offered any support for fatigue, pain, or sleep difficulties?

5. Family and Caregiver Support

- With your permission, are your family or caregivers included in talks about your care?
- Do they get the support and information they need?

Appendix 6. Guidance development flowchart