



Cancer and Dementia Scoping Project Final Report and Recommendations January 2025

Executive Summary

This report contains a summary of findings and recommendations from a project commissioned by Cheshire and Merseyside Cancer Alliance and delivered by the End of Life Partnership and Liverpool University Hospitals NHS Foundation Trust.

The project was commissioned to understand the support that is currently available for people with a dual diagnosis of cancer and dementia in Cheshire and Merseyside, and how this could be improved.

Age is a risk factor for both cancer and dementia, and the number of people living with both conditions (whether one or a dual diagnosis) is predicted to rise due to our ageing population.

Research by the Centre for Dementia Research at Leeds Beckett University found that of people aged 75+, 7.5% were living with both conditions. Based on this research, the estimated number of people in Cheshire and Merseyside with a dual diagnosis would be over 18,000, however there is currently no specific support for dual diagnosis in Cheshire and Merseyside.

A set of recommendations have been co-produced based on the project team's findings. Both the findings and recommendations are consistent with the literature search carried out as part of this project.

Recommendations for the Cancer Alliance and Partners:

1. Access to additional dementia expertise for cancer MDTs
2. Training for professionals
3. Education and Awareness Raising for Family Carers
4. Dementia Friendly Environments

Recommendations for further scoping/exploration

5. Explore the viability of a Patient Passport for people with dementia/cognitive issues to include guidance on reasonable adjustments
6. Scope the use of flagging on electronic patient records to highlight dementia diagnosis/cognitive issues and reasonable adjustments required.

Recommendations for wider system partners (outside scope of project but included for completeness)

7. Assign a named Dementia Specialist Nurse on diagnosis
8. Map post diagnostic support for dementia to support navigation

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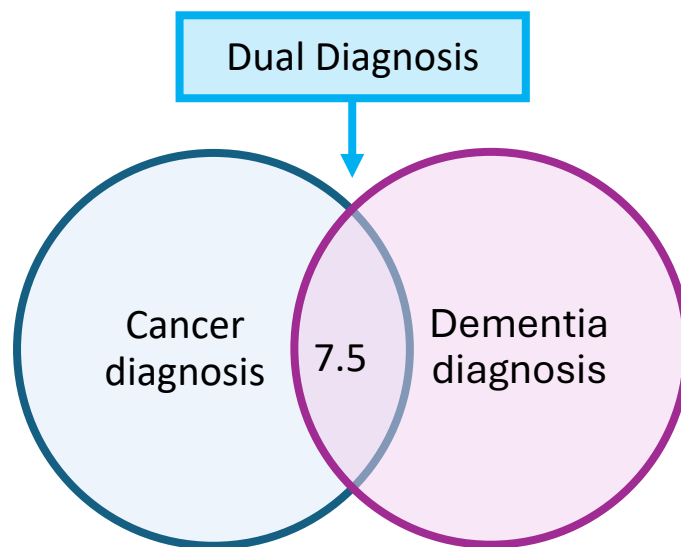
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Background to the project

Age is a risk factor for both cancer and dementia, and the number of people living with both conditions is predicted to rise due to our ageing population:

- 36% of cancer diagnoses made in the UK in 2015 were made in people aged 75+. By 2035 its anticipated that 46% of all diagnoses will be in the population aged 75+¹.
- There are currently estimated to be 982,000 people aged 65+ with dementia in the UK. This number is expected to rise to 1.4 million by 2040 ².

Research by the Centre for Dementia Research at Leeds Beckett University found that of people aged 75+, 7.5% were living with both conditions:



This project was commissioned by the Cheshire and Merseyside Cancer Alliance to understand the support that is currently available for people with a dual diagnosis of cancer and dementia in Cheshire and Merseyside, and how this could be improved.

Aims of the project

The first aim of the project was to scope:

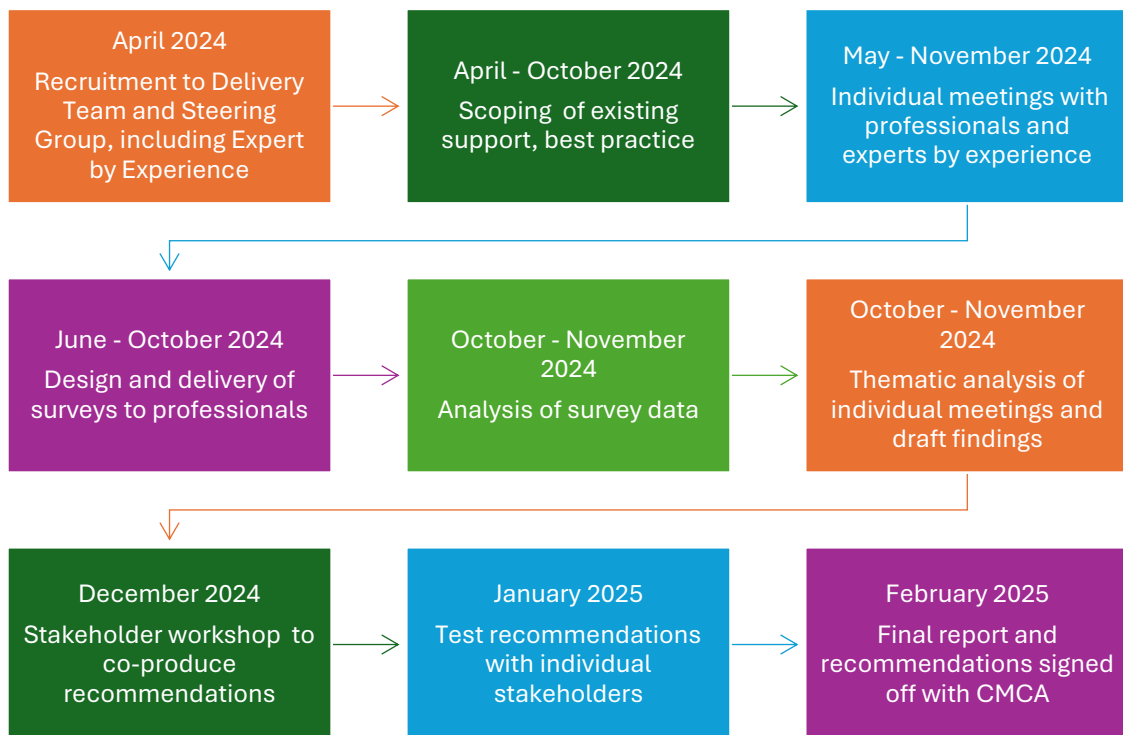
- Level of need – the expected numbers of people with a dual diagnosis of cancer and dementia resident within Cheshire and Merseyside ICB.
- Current provision within the ICB for people with a dual diagnosis of cancer and dementia and their carers
- Primary and Secondary Care professionals' skills, understanding and knowledge on best interest decisions that may inform suspected cancer referral / investigation practice for those with a known dementia diagnosis
- Existing work/research within Cheshire and Merseyside, nationally and beyond on best practice in providing support for people with a dual diagnosis and their carers

The second aim of the project was to develop a set of co-produced recommendations, based on the scoping, about how support for people with a dual diagnosis and their carers could be improved across Cheshire and Merseyside.

¹ [Cancer Statistics for the UK \(cancerresearchuk.org\)](http://cancerresearchuk.org)

² [How many people have dementia in the UK? | Alzheimer's Society](http://alzheimersociety.org.uk)

Approach



Recruitment to Delivery Team and Steering Group

Recruitment included identification of clinical leads for dementia and cancer and an Expert by Experience. Recruitment was led by Catherine Morgan-Jones, project lead from the End of Life Partnership (EOLP) as the organisation with a lead for project delivery.

Sara Jones (Admiral Nurse) was recruited as the clinical lead for dementia from EOLP's Advanced Dementia Support Team.

Katy Lobley (Principal Clinical Psychologist at the Cancer Psychology Service, Liverpool University Hospitals NHS Foundation Trust (LUHFT)) was recruited as the clinical lead for cancer via an Expression of Interest process shared with Acute Trusts across Cheshire and Merseyside.

The team was further enhanced by Poppy McNally (Assistant Psychologist) and Eleri Johnson (Trainee Psychologist) from the Liverpool Cancer Psychology Service.

To recruit the Expert by Experience, information about the project and a recruitment poster were circulated to a range of organisations including Councils for Voluntary Services, Dementia Support Groups and Cancer Support Groups across Cheshire and Merseyside. The project team were contacted by colleagues from a Macmillan Service who had identified a service user with relevant experience, Sheila Harvey, who was willing to be part of the Steering Group.

The Steering Group membership included the delivery team, Expert by Experience and Jen Kelly, Senior Transformation Manager for Personalised Care and Psychosocial Support on behalf of CMCA. The Steering Group worked to agreed Terms of Reference.

Scoping of existing support, best practice

To address the project aims of scoping current provision within the ICB for people with a dual diagnosis of cancer and dementia and scoping existing work/research on best practice, the team completed online/desktop research and a literature review.

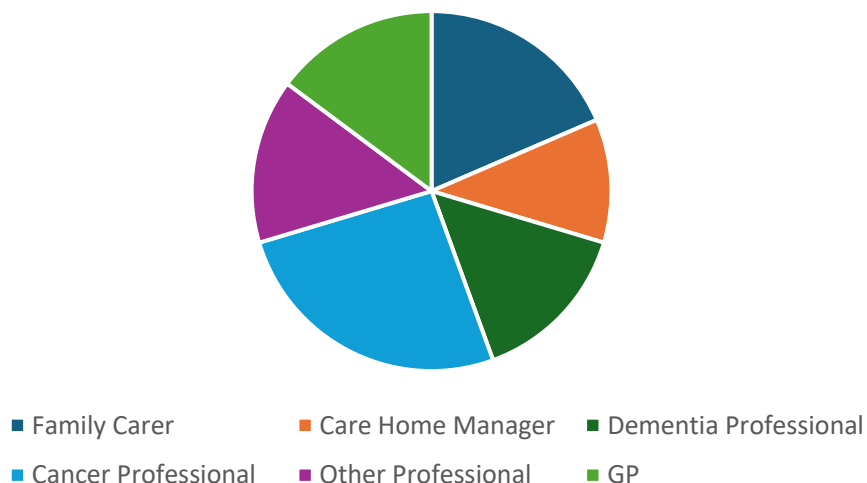
These identified limited information about services for dual diagnosis, with only one specific service identified at the Christie Hospital in Manchester ³. There is currently no specific support for dual diagnosis in Cheshire and Merseyside.

The Centre for Dementia Research at Leeds Beckett University has undertaken Cancer and Dementia in Hospitals Research (CANDEM). Findings from this study have been used by participating hospitals to inform changes to their environment and processes and have also informed the development of various resources, including leaflets for patients and carers, which are available via their website ⁴.

Individual meetings with professionals and Experts by Experience

To address the project aims of scoping current provision and gaining an understanding of professionals' skills, understanding and knowledge, the team set up meetings with individuals and teams to talk to them about their experiences of providing or receiving care.

A total of 27 conversations took place with professionals from different care settings and "Experts by Experience" - people with lived experience of caring for someone with dual diagnosis. Many of the conversations with staff and professionals also involved sharing their personal experiences with friends and family experiencing cancer and/or dementia, and were thus reflections of both personal and professional experience. A list of the organisations that took part in the project is shown in the Appendices.



A set of prompts was used to provide some structure, but the format for meetings was kept as open as possible so that team did not inadvertently limit the scope of people's comments. The meetings with individuals provided in-depth insights into challenges and good practice from their own services or experiences, and many of the people who participated in meetings made specific suggestions for improvements.

³ [Christie Hospital Psycho-oncology Team](#)

⁴ [CanDem Research | Centre for Dementia Research | Leeds Beckett University](#)

Design and delivery of surveys to professionals

As well as 1:1 conversations, the team provided opportunities for staff and professionals to provide their feedback and opinions via a more accessible anonymous survey. Five different surveys were set up for different care settings. They included core questions that appeared in all the surveys, and other questions tailored to the intended audience/care setting. Questions reflected the project aims, and themes that emerged from the first individual meetings.

A range of communication channels were used to make professionals aware of the surveys. This included the Integrated Care Board (ICB) newsletter for Primary Care, Care Home Forums, Cancer Nurse Quality Group Forums, organisational newsletters, and individual approaches to colleagues and organisational comms teams.

89 responses were received across the five surveys:

Survey Audience	% of responses
Acute Hospital Trusts	37% (of which 29% from LUHFT)
Care Homes	31%
Community Services	18%
Dementia Professionals	7%
Primary Care	7%

Surveys were received from all of the nine Places within Cheshire and Merseyside ICB. The higher figure from Liverpool reflects the fact that Liverpool University Hospitals NHS Foundation Trust (LUHFT) is the largest Acute Trust in the region, and the fact that project team were able to use their networks to encourage colleagues to take part in the project.

Place	% of responses
Cheshire East	13%
Cheshire West	11%
Halton	8%
Knowsley	2%
Liverpool	36%
Sefton	3%
St Helens	10%
Warrington	2%
Wirral	3%
Multiple Places	3%
Blank	7%
Not stated	2%

Responses were received from a range of professional groups. A more detailed breakdown of survey responses is shown in the Appendices.

Professional Group	% of responses
Care Home Manager	25 %
Specialist Nurse	21%
Nurse	13%
Other	12%
AHP	11%
Consultant	10%
Doctor	5%
HCA	2%

Analysis of survey data and thematic analysis of individual meetings

Qualitative and quantitative data and themes from the surveys and individual meetings were reviewed by the project team, and a number of key themes began to emerge. Some key learning from the project team is shown below, with the themes explored in more detail in the next section.

Dual Diagnosis

One of the key challenges put to the delivery team was that the project referred to dual diagnosis. Colleagues commented that they were often supporting someone with symptom of dementia, or mild cognitive impairment, but did not necessarily have a formal diagnosis. This reflects Alzheimer's Research UK findings that around 40% of those aged 65 or over thought to be living with dementia do not have a diagnosis⁵ and several project contributors stated that there were barriers to accessing diagnosis, mainly capacity and waiting lists.

Feedback from meeting participants was that the **project recommendations should include people whose presenting symptoms indicate dementia**. This would ensure that people are treated on the basis of need and presentation and would avoid excluding people who are awaiting diagnosis or for various reasons are not able to access a dementia diagnosis.

Systemic Issues

A high proportion of comments related to challenges that patients with other conditions also report e.g. poor communication and co-ordination of care across settings. These issues are not unique or specific to people with a dual diagnosis and are outside the scope of this project.

Access to dementia diagnosis was highlighted as a challenge and whilst this is also true for people without a potential dual diagnosis, there are specific implications for people with cancer diagnosis who have symptoms of dementia, where dementia assessment may be delayed due to cancer needs or treatment, or concerns about medication complexities.

⁵ [Diagnosis of dementia - Dementia Statistics Hub](#)

[Getting a dementia diagnosis](#) is key to unlocking access to personalised care and support, as well as accessing [treatments](#) that can help to control symptoms. A diagnosis helps enable people to plan ahead and identify any potential ways to improve their [brain health](#). An early and accurate diagnosis may offer greater opportunities to [take part in research](#), such as [clinical trials](#), increasing our chances of finding [life-changing treatments](#). It will also be crucial to [accessing these treatments](#) when they arrive.

Order of Diagnoses

In relation to dual diagnosis, the delivery team made no distinction with regards to the order that the diagnoses were made. However, **feedback focussed almost exclusively on situations where someone with a diagnosis of dementia received a subsequent diagnosis of cancer**, rather than the reverse. The only explicit reference to a cancer patient with suspected dementia came from a GP who reflected that they would want to rule out the possibility of brain metastases being a cause of symptoms before referring to a memory clinic. This finding may simply reflect the experiences of professionals taking part in the project, but correlates with survey feedback that indicates that people working in cancer services would welcome the opportunity to develop their knowledge and skills in dementia.

Support after Diagnosis

For people with experience of both conditions, a contrast was made between how services, individuals and society respond after a cancer diagnosis versus a dementia diagnosis. National targets for cancer diagnosis, treatment and follow up have resulted in well-defined pathways and timely interventions, with a range of roles within the NHS and voluntary sector to support patients throughout their treatment. Thus there is a clear system of monitoring and accountability relating to patient care for cancer services, whereas there is no current equivalent for dementia.

As highlighted above, around 40% of people thought to be living with dementia do not have a diagnosis. For those who do access Memory Clinics, **the support available after a dementia diagnosis is variable and depends on local commissioning arrangements** for roles such as Dementia Advisors. This reflects the findings of an audit of Memory Assessment Services by the Healthcare Quality Improvement Partnership which found that nationally there is a high level of variance in post-diagnostic interventions and access to NICE recommended interventions (e.g. only 31% of people eligible for cognitive stimulation therapy were offered this support).⁶

Access to other support though such as peer support groups provided by the voluntary sector may come and go depending on the availability of funding. This has an impact on patients and carers who are vulnerable to fluctuating service provision and also has the potential to add to the burden on statutory services if patients are unable to access this type of support that complements core provision. It is also difficult for staff to refer to services when provision, referral criteria and waiting lists change, as keeping on top of this fluctuating picture is a large demand on time.

Meeting contributors also observed that **societal perceptions of the two conditions is very different** and that the stigma that remains around dementia is reminiscent of attitudes to cancer 30 years ago. This compounds the sense of isolation experienced and reported by both carers and professionals.

Opportunities to Share Learning

A number of opportunities to learn from other services were identified. This includes learning from teams such as Frailty that frequently deal with multiple morbidities, and services such as learning disabilities, where implementing reasonable adjustments is routine.

⁶ [Dementia audit: Memory Assessment Services 2023/2024 \(NAD\) – HQIP](#)

Experience of Carers

In meetings with Experts by Experience, there were two key messages. The first is the importance of listening to and respecting the view of carers, who generally know the patient best. The second theme was that positive experiences were almost always due to professionals making simple changes and adjustments to ensure that care was person-centred, suggesting that sometimes simple acts can have the biggest, and most lasting impact!

Co-production of recommendations

A workshop was held to share the project findings and co-produce recommendations in response. Everyone who had taken part in an individual meeting was invited to attend, along with colleagues from both dementia and cancer services and fourteen individuals attending, including the project delivery team.

Recommendations were then shared with stakeholders based on their level of interest in the potential implementation of proposed improvements and comments incorporated into final recommendations.

Findings - Level of Need

Population with dual diagnosis (current figures)

The Centre for Dementia Research estimates that 7.5% of the population aged 75+ have a dual diagnosis of cancer and dementia. This would suggest 18,300⁷ people living with a dual diagnosis in Cheshire and Merseyside.

Based on the incidence cited above, the table below shows the expected number of people aged 75+ with a dual diagnosis within each of the nine Places within Cheshire and Merseyside.

These figures are likely to be an underestimate as a) the figures only reflect the population aged 75+ and b) dementia is generally underdiagnosed, with diagnosis rates varying between Places.

Place	Population aged 75+	% of population aged 75+	Estimated number of people aged 75+ with dual diagnosis *
Cheshire East	45,727	19%	3,430
Cheshire West & Chester	37,844	15%	2,838
Halton	10,353	4%	776
Warrington	20,016	8%	1,501
Knowsley	11,375	5%	853
Liverpool	33,365	14%	2,502
Sefton	32,892	13%	2,467
St. Helens	18,249	7%	1,369
Wirral	34,402	14%	2,580
Cheshire and Merseyside	244,223		18,316
England	5,146,324		

* Based on 7.5% of the population aged 75+, reflecting findings from the Centre for Dementia Research.

Research indicates that up to 40% of older patients present with cognitive issues that can impair their capacity to make complex decisions about treatment, adhere to treatment plans and recognise symptoms of toxicity that might require medical attention⁸. This would include people who may not have formal diagnosis, but whose presentation indicates dementia.

⁷ [Estimates of the population for England and Wales - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk)

⁸ [Treating and caring for an ageing population | Cancer Research UK](https://www.cancerresearchuk.org)

Population with dual diagnosis (Future Projections)

- The Office for National Statistics predicts that by 2050, a quarter of the UK population will be aged 65 or over.
- The number of people over 75 diagnosed with cancer is set to rise by 80% between 2015 and 2035 ⁹.
- The number of people living with dementia was estimated to be close to one million in 2021 (944,000). By 2050 this figure is expected to rise to 1.6 million ¹⁰.

Even if the % of people with both conditions remains at 7.5% of the population aged 75+, the number of people within this age group will expand due to the UK's ageing population, therefore so will the number of people with both diagnoses. Considering this anticipated growth in demand, it is even more important that services supporting people with cancer or dementia become better equipped to support the increasingly complex needs of patients with co-morbidities.

Features of people with dual diagnosis

Research by Leeds Beckett University identified that people with dual diagnosis differ from people with cancer alone:

- They are older
- More likely to live in a care home
- More likely to have additional comorbidities (alongside having cancer and dementia)
- Use more healthcare resources (e.g. GP appointments and prescriptions)
- Dual diagnosis was more likely among people with a diagnosis of, breast, prostate and bladder cancers

Health Inequalities

The biggest risk factor for both cancer and dementia is age. Other aspects of health inequalities that affect these two conditions individually include:

	Cancer ¹¹	Dementia ¹²
Gender		Women are more likely to develop dementia than men
Socioeconomic status	People in the most deprived areas are <ul style="list-style-type: none">• 20% more likely to have their cancer diagnosed at a late stage• Receive only half the number of referrals to early stage clinical trials• Face almost 25% more emergency admissions in the last year of life compared to people in the least deprived areas• Deprivation significantly impacts cancer incidence and survival rates. Lifestyle factors associated with increased cancer risk (such as smoking and obesity) are more common in deprived populations.	People in lower socioeconomic groups in the UK are exposed to a higher risk of developing dementia, and may face additional barriers such as limited access to healthcare services

⁹ [Treating and caring for an ageing population | Cancer Research UK](#)

¹⁰ [Prevalence and incidence - Dementia Statistics Hub](#)

¹¹ [There are higher rates of cancer in the most deprived areas - NHS England Digital](#)

¹² [Inequalities in dementia - Dementia Statistics Hub](#)

	Cancer ¹¹	Dementia ¹²
Ethnicity	<ul style="list-style-type: none"> • People in the White British ethnicity group have higher mortality rates than most ethnic minority groups for several types of cancers and dementia. • People in the Black Caribbean ethnicity group had the highest age-standardised mortality rates for blood cancer and prostate cancer 	<ul style="list-style-type: none"> • People from Black, Asian and minority ethnic communities living in the UK may be at a higher risk of developing dementia due to increased exposure to dementia risk factors. • Historical and current systemic racism within various structures including health services have meant that many minoritised communities do not trust or engage with NHS information or services in relation to dementia or cancer. Thus individuals from these communities may not feel confident in engaging with services for assessment or treatment, leading to further inequities.
Down's Syndrome		<ul style="list-style-type: none"> • People with Learning Disabilities, including Down's Syndrome are at a higher risk of developing dementia. • The Royal college of Psychiatrists estimate that people with Learning Disabilities over 60 are 2 - 3 times more likely to have dementia, and also that they are likely to be diagnosed at a younger age. • This may relate to multiple factors, but also be influenced by higher levels of social deprivation and health inequalities experienced by people with learning disabilities.
Rurality	Socioeconomic deprivation is compounded in rural areas due to the time and distance of travel to services and infrastructure and little or no public transport. As people age and develop health conditions, this may lead to risk of social isolation and difficulty accessing the support they need.	

Barriers to treatment for people with dual diagnosis

NHS services for physical health problems, including cancer, may not be equipped to provide the holistic care required for someone with dementia¹³. Cancer outcomes for people with dementia, when compared to those without indicate that people experience:

- Later diagnosis
- Less or no treatment
- More complications
- Poorer survival rates

Leeds Beckett findings state that “Having dementia adds a great deal of complexity to cancer treatment and care. For example, decision making around cancer treatment becomes more complex. There are challenges around capacity, understanding and retaining information, and balancing quality against quantity of life”. Other challenges when supporting someone with a dual diagnosis include communication and the environment.

All of the above suggests that dementia is a barrier to treatment for cancer and could be considered to be a health inequality in its own right. The project team had one discussion with a family carer who perceived that a family member was not being offered treatment due to their dementia diagnosis. Without making a judgement as to whether or not treatment was being “denied”, there was clearly a breakdown in communication about the rationale for clinical decisions in this particular case.

¹³ Hynes et al, 2022

Findings – Current Provision

The following section of this report summarises the data from the five surveys a thematic analysis of free text responses to the online surveys and notes of individual meetings. Findings are aligned to the six Ambitions for Palliative and End of Life Care ¹⁴, which provided a useful a framework and definitions for the thematic analysis and reflects the palliative nature of dementia.

The diagram below shows the proportion of feedback that relates to each of the six “Ambitions” – larger boxes indicate more comments and feedback.



The following pages contain a summary of feedback received against these six themes, along with examples of good practice within the services that the team were able to identify and visit or discuss in depth, and recommendations where applicable.

Whilst some text is shown in “speech bubbles”, this should not be interpreted as being a verbatim quote.

¹⁴ [ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf](#)

Multi-disciplinary team members responding to our survey expressed concern that their MDT did not routinely include specialists who could add value to a discussion about an older patient, such as social workers, occupational therapists, physiotherapists, dieticians, and pharmacists

This quote from Cancer Research UK ¹⁵ summarises feedback received from project participants about the challenges of co-ordinating care for people with a dual diagnosis.

Feedback

This was the most cited issue for medics (Doctors and Consultants) and correspondingly, it was cited more often in acute trusts and primary care than in care homes and community settings. Numerous references were made to silo working, barriers between organisations, care settings and physical and mental health. There were also concerns that lack of co-ordination between services, and ambiguity about decision making could contribute to clinical and safeguarding risks for people with a dual diagnosis. Professionals acknowledged the limitations of their clinical expertise when supporting people with a dual diagnosis and were keen to have access to ongoing advice and support from people with knowledge of other condition.

Survey respondents from acute trusts rated access to a Dementia Specialist Nurse as their top priority for service improvement and participants working in acute care also wanted to explore ways that dementia professionals could contribute to the well-established practice of multi-disciplinary team (MDT) meetings discussions within cancer services. This has the potential to improve the way that legal frameworks such as the Mental Capacity Act and Best Interests Decisions are applied as well as ensure that clinical care reflects the patient's dementia diagnosis. One consultant who proposed this approach noted that it would require buy-in at a senior level (clinical and managerial) within their acute trust. It was also important that Dementia specialists joining a cancer MDT have the confidence to challenge and that they are well supported by senior clinicians.

Care homes also identified a need for greater co-ordination and said they would benefit from access to advice and support from specialists in both cancer and dementia care. 43% of care homes that responded to the survey reported that they had access to a Macmillan Nurse, whilst just 25% had access to Admiral Nurse/Dementia Specialist input.

Good Practice

The Christie Hospital in Manchester has a dedicated dementia service that supports cancer teams who are treating people with dual diagnosis. The team have supported changes to clinical pathways and are regularly brought into MDT discussions, although it has taken time to establish this approach.

At one site at LUHFT, a Dementia nurse specialist sits in on best interest meetings with patient, carers and other professionals. They are able to help weigh the pros and cons of treatments as part of an MDT approach and help support families with decision-making. Although this service provides similar input to that at Christie, in this case it is limited to some wards for older people, and is not embedded in the cancer nursing teams.

¹⁵ Advancing care, advancing years: Improving cancer treatment and care for an ageing population. Cancer Research UK, June 2018

Recommendation

Recommendation 1: Access to additional dementia expertise for cancer MDTs

Due to the ongoing day-to-day challenges caring for someone with dementia, the cancer diagnosis appeared to be of secondary importance (to carers) ... Carers described ethical challenges of balancing quality of life alongside potential challenges of cancer care ... Carers wanted to maintain personal integrity and identity of the person living with dementia and cancer ... whilst participants valued this, they described it as challenging.

Feedback

This theme relates to the needs of family carers. The research quoted above ¹⁶ highlights some of the key challenges that carers describe in relation to their own experiences, and these were iterated by the people who took part in this project.

One of the key themes highlighted by carers was a lack of consistent support after a dementia diagnosis. Although some people had accessed a Dementia Advisor or Admiral Nurse, experiences were variable which may reflect the fact that these roles are not commissioned on a consistent basis across Cheshire and Merseyside. This is compounded by the fact that support from the charitable and community sector may fluctuate based on the availability of funding and volunteer support.

Carers reported having a limited understanding of where they were on the dementia pathway and felt quite lost after a diagnosis. They also reported feeling isolated. This is a commonly reported concern among carers, however the specific challenges of dual diagnosis and the perception that there are very few others in the same situation may compound this experience.

This situation was summed up by a cancer support service provider who stated they were unable to offer the level of support the person with dementia needed, as an additional staff member would be needed to provide a reasonable adjustments (support with coming and going to and from the room) and as a charity they didn't have the staff for this. This situation highlights a number of the findings from this report, including carer reliance on the charity sector which has inconsistent funding, and single stream funding for either cancer or dementia, which means that people with Dual Diagnosis are unable to access support, and thus carers have less respite and are more isolated.

There are specific emotional burdens associated with caring for someone with a dual diagnosis, including the impact of having to make decisions on behalf of a loved one whilst dealing with their own anticipatory grief. The research quoted above describes in detail the experiences of carers who continue to question their decisions long after a family member has died.

Of the carers who took part in individual meetings, four made reference to managing medications and their worries about doing this safely. Carers also commented that whilst signposting services such as social prescribing were a good source of information about what is in the community, "It is exhausting following this through when there is everything else to cope with".

Professionals also referred to carers in their comments, and recognised that communication and managing expectations are significant challenges, compounded by the fact that dementia is not always acknowledged as being

¹⁶ Experiences of Comorbid Dementia and Cancer: A Qualitative Systematic Review and Empirical Study Georgie-Anne F. Quinn (2024)

a palliative condition. Professionals also acknowledge that carers own health and ability to provide the necessary support, including management of medication, was a factor in making decisions to treat in cases of dual diagnosis.

Recommendations

Recommendation 3: Education and Awareness Raising for Family Carers

Recommendation 7: Assign a named dementia nurse on diagnosis

Recommendation 8: Mapping exercise of post diagnostic support for dementia to support navigation

Don't just focus on memory aspects of dementia, physical, behavioural and mobility challenges are just as significant (meeting participant).

Symptom Management

Symptom management was the most frequently cited issue for Care Home Managers and Nurses and is made more complex for people with dual diagnosis due to challenges with understanding, communication and reporting. Professionals expressed concern that people with dual diagnosis may not be able to accurately report symptoms or side effects of treatment e.g. neuropathy, disorientation and nausea and Survey respondents from acute trusts rated communication with patients as being their biggest challenge.

Primary care colleagues acknowledged that care homes are experienced at managing people with multi-morbidities but may not have the knowledge and skills to manage symptoms of cancer and this was reinforced by experts by experience. The challenge of pain management and "comfort" was cited on multiple occasions by clinicians and others, reflecting distress it causes the person and those caring for them. It was also acknowledged that delirium and agitation are common to both conditions. There is a risk that this is attributed to dementia, but underlying cause may be due to cancer and/or unmanaged pain.

The impact of the patient's environment on behaviours was also described by experts by experience and professionals, noting that symptoms may worsen on admission to a hospital ward, where a change in routine, sensory triggers, sense of isolation or restriction and other factors might make inpatient admissions particularly challenging.

Prescribing

Professionals and Experts by Experience described concerns about prescribing and medication management, with examples given of delayed discharges due to lack of clarity over medication management for patients living alone. Family members described the challenge of managing complex medication on behalf of a loved one and their anxiety about getting things "wrong". Some people had come up with solutions including designing their own medication charts, however it should be noted that not everyone with dual diagnosis lives with other people, so there may be specific risks in relation to medication compliance for people who live alone.

Arrangements for prescribing also highlighted the issue of silo working and lack of co-ordination, with different medications being prescribed by different organisations and specialisms, which adds to the confusion and frustration felt by family carers.

Holistic care

As exemplified by the quote above, both professionals and Experts by Experience noted the importance of supporting all aspects of wellbeing, including mental wellbeing. Care homes in particular emphasised their focus on promoting of quality of life, independence and comfort for their residents.

Professionals shared a number of examples of good practice include provision of psycho-social support for patients and families, access to financial and benefits support. However, Experts by Experience and staff who contributed to this project identified clear gaps in provision.

The National Cancer Patient Experience Survey 2023 ¹⁷, showed that people with an additional diagnosis of dementia were reported that they were offered information about how to get financial help or benefits less often than people without dual diagnosis (59.5% of patients with dementia vs 70.1% without).

Many cancer services make use of the Macmillan Concerns Checklist as part of a holistic needs assessment, however Experts by Experience and staff who contributed to the project have identified gaps in provision that are not being addressed via this process.

Whilst the Concerns Checklist is a well-recognised resource to support holistic care, it has limitations for people with a dual diagnosis;

- The checklist includes an option for cancer patients to highlight concerns about memory or concentration or other health issues, however there is no explicit reference to dementia or adjustments.
- Reliance on the patient sharing information with the professional, rather than recording dementia status on patient records that can be accessed by other professionals.

Good Practice

Some dementia services are introducing Artificial Intelligence-based apps to detect pain based on facial features which may help alleviate challenges of communicating cancer-related experiences for people with a dual diagnosis ¹⁸.

¹⁷ [Tell us about your experience of cancer care - National Cancer Patient Experience Survey](#)

¹⁸ Baird et al (2023)

Professionals should support appropriate decision making either by optimising the ability of individual to make decisions, or ensuring "good" best interest decision making.

Mental Capacity and Best Interests Decisions

The Montgomery ruling places an onus on professionals to explain any potential risks (no matter how small) to patients to gain informed consent to care. For a patient with dual diagnosis, their mental capacity to consent to specific decisions should be assessed, and in the event that the patient is unable to give informed consent, professionals should work with the patient and carers to take a decision in the patient's Best Interests.

The National Cancer Patient Experience Survey 2023¹⁹ showed that people living with dementia expressed lower levels of satisfaction with:

- Referral for cancer diagnosis explained in a way the patient could fully understand (56.7% of patients with dementia vs 66.6% without)
- Diagnostic test results were explained in a way the patient could completely understand (72.8% vs 78.5%)
- Cancer diagnosis explained in a way the patient could completely understand (68% vs 76.7%)

Professionals concerns about putting a patient through potentially distressing experiences should not override the patient's right to be involved in decision making if they are able and/or being part of a formal best interests approach. Recent research suggests that not applying the relevant legal frameworks and failure to involve patients and carers could constitute a breach of human rights²⁰, although no specific examples of this were identified during this work.

Findings from the project surveys and individual meetings were that professionals are not always confident in applying the Mental Capacity Act²¹, and that Best Interests²² discussions and decisions are not always as inclusive as they should be. Experts by Experience gave examples of being informed about a best interests meeting after the event, having had no input into the discussions.

Professionals emphasised the need to weigh the pros and cons of referral for diagnostic investigations and/or treatment, taking into account the patient's ability to tolerate and comply with investigations and/or treatment. Nursing colleagues perceived that they are well placed to advocate for the patient due to their insights into side effects and impacts of treatment on the patient's activities of daily living etc. Professionals also acknowledged that decisions are difficult and complex for patients and carers, who may need multiple conversations to reach a decision, and that healthcare systems are not set up to accommodate this. In addition, pressure around cancer waiting times and outcome data may result in staff being less open to complex decision making, as this may delay treatment, however this should not take priority over the correct use of legal frameworks (noting that no specific evidence of this was found during scoping).

Advance Care Planning

Dementia professionals in particular highlighted the importance of having plans in place for future care needs, and the value of having power of attorney arrangements agreed, particularly when someone has a cancer diagnosis and decisions about treatment may need to be taken relatively quickly.

¹⁹ National Cancer Patient Experience Survey

²⁰ Experiences of Comorbid Dementia and Cancer: A Qualitative Systematic Review and Empirical Study Georgie-Anne F. Quinn (2024)

²¹ [Mental Capacity Act 2005](#)

²² [Quality statement 4: Best interests decision making | Decision making and mental capacity | Quality standards | NICE](#)

Good Practice

Dementia Service at the Christie Hospital includes providing support to surgeons and ward staff around treatment for people with dementia, including best interests decision making.

“Accounts of people living with cancer and dementia consistently evidence their lack of power in comparison to caregivers whose voices were more often believed, heard, and understood; and professionals, who possessed knowledge and abilities to finalise decisions. Current practice raises significant issues diminishing the basic legal rights and decision-making power of people living with cancer and dementia”.

Barriers

Over the course of the project, the team heard evidence of a number of different barriers that people with dual diagnosis and their carers face. This includes not feeling heard by professionals (reiterated in the findings of recent research quoted ²³ above) and access to dementia diagnosis and treatment. This in turn creates a barrier to other support which may be conditional on a diagnosis having been received. Participants also observed that dementia symptoms may be a barrier or exclusion criteria (real or perceived) when accessing mainstream services including cancer treatment.

Practical issues, such as transport, appointment times and the physical environment had a significant impact on the experience of care. Experts by Experience noted a number of positive experiences where simple adjustments had been put in place such as being able to remain with the patient during diagnostic investigations/treatment, allowing enough time for discussions etc. This is consistent with findings from research ²⁴ that the standardised NHS pathway for cancer care pathway doesn't typically accommodate reasonable adjustments for individuals with dementia and this is often further compromised by challenges such as unclear signage, visually challenging environments, automated electronic appointment systems, busy environments with lots of people and noise, difficulty with travel and parking. Although many staff and services are keen to provide adjustments, the issues with communication and information sharing means that often needs are not identified prior to people accessing services.

Reasonable Adjustments

One professional observed that “Extra safeguarding is needed when patients with dementia access our support, which is an extra demand”, however not making an adjustment by providing additional support would be in breach of the Equality Act, which states that health and social care organisations must take steps to remove the barriers individuals face because of disability and must make it as easy for disabled people to use services as it is for people who are not disabled.

Reasonable adjustments are a legal requirement to make sure health services are accessible and NHS England have developed a Reasonable Adjustment Digital Flag on the NHS Spine which enables health and care professionals to record, share and view details of reasonable adjustments, wherever the person is being treated ²⁵. Implementing reasonable adjustments for people with dual diagnosis would also benefit other groups e.g. neurodiverse groups, people with sensory impairments.

Good Practice

A number of participants highlighted examples of good practice within their own services, or opportunities to learn from e.g. Learning Disability services, where implementing reasonable adjustments is a matter of routine. Unfortunately, many of these initiatives are also carried out in silos within specific services e.g. Neuro Diversity, Learning Disabilities or older people's services, despite sharing common goals and experiences. The impact of the

²³ Experiences of Comorbid Dementia and Cancer: A Qualitative Systematic Review and Empirical Study. Georgie-Anne F. Quinn (2024)

²⁴ Witham et al. (2018), Farrington et al. (2023), Ashley et al. (2020), Martin et al. (2021)

²⁵ [DAPB4019: Reasonable Adjustment Digital Flag - NHS England Digital](#)

different initiatives to implement Reasonable Adjustments would be magnified if staff working across diverse patient groups had opportunities to share their work across services.

Recommendations

Recommendation 4: Share learning about Dementia Friendly Environments to support the implementation of reasonable adjustments, recognising that these adaptations may also benefit groups with other needs.

Recommendation 5: Explore the viability of a Patient Passport for people with dementia/cognitive issues to include guidance on reasonable adjustments required.

Recommendation 6: Scope the use of flagging on electronic patient records to highlight dementia diagnosis/cognitive issues and reasonable adjustments required.

Confidence Levels

All of the surveys by the delivery team included questions about the levels of confidence in providing care for, and communicating with, people with a dual diagnosis.

One member of the project team commented that “I was struck by my encounters by people who were just working incredibly hard to make a difference. There are lots of caring individuals out there wanting to do the best for patients, and aware that in some areas they lack knowledge and skills to deliver the care they want to. Also that this desire to care is often restricted by communication barriers between services, access to specialist support and limited resources”.

Dementia and nursing care homes had the highest level of confidence in providing care for and in communicating with people with dual diagnosis (7.5 and 7.9 out of 10), reflecting the frequency of contact within these care settings with people with dual diagnosis.

Staff working in acute care settings had the lowest levels of confidence in providing care and communication (5.9 and 6.0 out of 10 respectively), which may reflect the limited contact with people with dual diagnosis (reported as monthly).

Training Topics

The surveys also included questions about training needs, with staff asked to prioritise different topics.

- Acute Trusts prioritised Reasonable Adjustments, Communication skills and how dual diagnosis of cancer and dementia affect assessment and treatment
- Care Homes prioritised Communication Skills and Reasonable Adjustments for Residents.

Implementation

When considering education training in relation to dual diagnosis, there are two main “workforces” to be targeted. The first is professionals working in cancer care, the majority of whom are based in NHS acute trusts, although cancer services are also delivered through organisations including Macmillan Cancer Support, Maggie’s and Marie Curie. Staff working in NHS trusts have access to the CMCA Cancer Academy for education and training resources.

The second workforce is professionals working in dementia care. This is a much more diverse group of staff, with a wide range of roles working across the NHS, Care Homes and other care settings. Roll out of training would therefore be more of a challenge and should make use of existing training infrastructure e.g. Palliative Care Education Hubs, mandatory training programmes.

Recommendation

Recommendation 2: Additional, advanced training for professionals

Recommendations

The following recommendations reflect the discussions held with a stakeholder group in December 2024 and suggestions made at individual meetings or via survey responses.

Resource implications

Low - could be implemented within existing staff resource/no additional investment

Medium - could be implemented within existing staff resource plus some additional investment

High – requires additional staff resource and significant additional investment

Timescales for Implementation

Short term – within 6 months

Medium term – between 6 and 12 months

Long term – 12 months +

Summary of recommendations for Cancer Alliance and Partners

Recommendation	Resource Implications	Timescales for Implementation
1) Access to additional Dementia expertise for cancer MDTs	Variable	Medium term
2) Additional, advanced training for professionals	Medium	Short term
3) Education and Awareness Raising for Family Carers	Medium	Short term
4) Dementia Friendly Environments	Variable	Short term

Summary of recommendations for further scoping/exploration

Recommendation	Resource Implications	Timescales for Implementation
5) Explore the viability of a Patient Passport for people with dementia/cognitive issues to include guidance on reasonable adjustments	Medium	Medium term
6) Scope the use of flagging on electronic patient records to highlight dementia diagnosis/cognitive issues and reasonable adjustments.	Low	Medium term

Summary of recommendations for wider system partners (included for completeness)

Recommendation	Resource Implications	Timescales for Implementation
7) Assign a named Dementia Specialist Nurse on diagnosis	High	Long term
8) Mapping exercise of post diagnostic support for dementia to support navigation	Low	Medium term

Recommendation 1 Access to additional Dementia expertise for cancer MDTs	
Description	<ul style="list-style-type: none"> • This approach aligns with recommendations and good practice re Cancer MDT working from the Royal College of Radiologists. Although these relate to Frailty, many of the same principles apply to people with dementia and there is overlap between the two cohorts. • Options include <ul style="list-style-type: none"> – Preferred option - create additional resource within existing Dementia specialist teams to provide capacity to support cancer MDTs. Job descriptions and work plans would need to specify that cancer MDT is an explicit part of these role to ensure that capacity is protected. – Making use of existing Admiral Nurse/ Specialist Dementia Nurse expertise within own Trust. Job descriptions and work plans would need to be redesigned to specify that cancer MDT becomes an explicit part of the role. The disadvantage of this option is that resources are already stretched and will face increasing demand as the population with dementia grows and without a specific focus on support for people with dual diagnosis, the situation for this cohort is unlikely to improve. – If there is no current resource within an organisation, it may be possible to put arrangements in place with other providers to give this support and expertise via a Service Level Agreement. This would need to make specific reference to supporting people with dual diagnosis throughout their cancer treatment. – Based on prevalence and expected caseload, recruitment to a specific role for dual diagnosis. The remit of this post would include providing training for cancer staff, case consultation, family communication, reviewing adjustments, specialist advice for inpatient and community, liaison with dementia services, support with discharge planning/liaison with hospices and linking with 3rd sector support. • Importance of having buy in and modelling from senior clinicians within cancer care so that dementia specialist input and challenge is valued by the cancer MDT • Build on existing good practice from Peri Operative Care for Older People Service (POPS) within LUHFT in terms of multi-disciplinary working • The limitations of this approach are that whilst it could have a significant positive impact for people with dual diagnosis whilst they are undergoing cancer treatment, once this treatment ends they will no longer have the support of the Dementia Specialist Nurse, compounding the feedback from Experts by Experience about the sense of isolation for carers of people with dementia.
Lead organisation	Acute trusts providing cancer care.
Resource implications	<ul style="list-style-type: none"> • Variable, dependent on existing staffing levels and capacity to support MDTs on an ad hoc basis. • Would need leadership at senior level, finances, management structure to provide support for roles to avoid isolation. • Practical issues relating to who would recruit/employ any posts, access to clinical records across cancer and dementia services if these are held by different trusts etc.
Timescales for implementation	Medium term (6 – 12 months). Longer term if recruitment is required.
External evidence base/examples of good practice and resources	Implementing frailty assessment and management in oncology services The Royal College of Radiologists (rcr.ac.uk)

Centre for Perioperative Care guidance on surgery also emphasises pathway and interventions around cognitive needs. [Guidelines | Centre for Perioperative Care \(cpoc.org.uk\)](https://www.cpoc.org.uk/guidelines)

Recommendation 2 Training for professionals	
Description	<p>Based on the findings of this project, the starting point of an education programme should be to increase understanding of both cancer and dementia among people who are not specialists in the other condition. (See also Appendix 5).</p> <p>Ideally, training would be developed and delivered by Cancer professionals to Dementia professionals and vice versa, however as a starting point some more generic training resources could be used at a level appropriate to different staff groups.</p> <p>Building on the general level of awareness obtained through e.g. statutory and mandatory training programmes, more speciality specific/advanced training on the following would be beneficial,</p> <ul style="list-style-type: none"> – Communication skills and use of Communication Aids – Reasonable adjustments – Mental Capacity Act and Best Interests decisions <p>Specific training on dual diagnosis could also be developed as a longer term ambition.</p>
Lead organisation	<ul style="list-style-type: none"> • The cancer workforce are employed by NHS acute Trusts and are relatively easy to identify and engage. • The workforce supporting people with dementia is employed by a diverse range of organisations, including NHS Trusts, Care Homes, Domiciliary Care Agencies etc. • Advice should be taken on the best routes to engage other groups of staff e.g. primary care, social workers.
Resource implications	<p>Medium level of resource implications:</p> <ul style="list-style-type: none"> • There is an opportunity to use the Cheshire and Merseyside Cancer Alliance’s Cancer Academy platform to disseminate core NHS dementia training to the cancer workforce. This is an existing resource and therefore minimal additional resource would be required to add links to existing training modules etc. • The dementia workforce is more diverse in terms of care setting, role and the number of employers involved. These care settings can be signposted to the Cancer Academy which includes a wide range of online cancer education and training including webinars. EOLP’s experience of extensive delivery of training to Care Homes is that these care settings prefer face to face training so other formats of training should also be considered to accommodate this. • If specific training on dual diagnosis is to be developed, this would require funding/expertise to develop a new resource.
Timescales for implementation	Short term – within 6 months
External evidence base/examples of good practice and resources	<p>For Oncologists: Frailty eLearning course British Geriatrics Society (bgs.org.uk)</p> <p>For cancer teams: dementiafriends.org.uk</p> <p>For care homes: Macmillan Learning Hub</p> <p>Communication Skills: Advanced Communication Skills Training</p> <p>For NHS teams: Mental Capacity Act - eLearning for healthcare</p> <p>Examples of reasonable adjustments in practice EHRC</p>

Recommendation 3 Education and Awareness Raising for family carers	
Description	<ul style="list-style-type: none"> • Education and Awareness Raising programmes for family carers, building on learning from e.g. East Cheshire Hospice, End of Life Partnership, Alzheimer’s Society etc. about content, engaging different professionals to contribute on a range of topics. • Suggested content based on feedback from stakeholder group includes <ul style="list-style-type: none"> – An overview of cancer and dementia to increase understanding – Advance Care planning, including Power of Attorney – Caring at end of life – Access to national and local support and resources • Provide opportunities for Experts by Experience to co-design and co-deliver training.
Lead organisation	TBC
Resource implications	Design and delivery of training would require funding. Content should be co-produced with Experts by Experience.
Timescales for implementation	Short term – within 6 months
External evidence base/examples of good practice and resources	dementiafriends.org.uk Cancer information and support Macmillan Cancer Support Confidence to Care at End of Life The End of Life Partnership How to plan for the future The End of Life Partnership Understanding dementia The End of Life Partnership

Recommendation 4 Dementia Friendly Environments	
Description	<ul style="list-style-type: none"> • Audit cancer services to identify environmental improvements that would make buildings and facilities more dementia friendly. • Ensure that dementia friendly design is planned into any renovations, new build planning processes etc.
Lead organisation	Cancer Service Providers.
Resource implications	Variable depending on changes required.
Timescales for implementation	Short term – within 6 months
External evidence base/examples of good practice and resources	NHS England » Health Building Note 08-02: Dementia-friendly health and social care environments Publications — Dementia Services Development Centre

Recommendation 5	Explore the viability of a Patient Passport for people with dementia/cognitive issues to include guidance on reasonable adjustments required
Description	<ul style="list-style-type: none"> • Explore the current use of patient passports within acute trusts including uptake of this type of documentation (e.g. Alzheimer’s Society “All About Me” documentation in use at LUHFT, Red Bag Schemes). • Work with staff and professionals to assess the value and effectiveness of this type of document and gain feedback on the use of this approach for people with dual diagnosis, noting that published evidence suggests that there is little evidence of improved care as a result of introducing this type of documentation. • Assuming positive feedback, opportunity to co-design a document with Experts by Experience that includes information about communication needs, reasonable adjustments etc. Note that studies on the use of this type of documentation note that having multiple templates reduces their effectiveness, so it would be advisable to adapt existing work, rather than duplicating.
Lead organisation	Acute Trusts
Resource implications	Medium
Timescales for implementation	Medium term (6 – 12 months)
External evidence base/examples of good practice and resources	NHS England » Health and care passports Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review - King's College London Patient-held records in cancer and palliative care: A randomized, prospective trial

Recommendation 6	Scope the use of flagging on electronic patient records to highlight dementia diagnosis/cognitive issues and reasonable adjustments required.
Description	<ul style="list-style-type: none"> • Review what flagging options are already available within electronic patient record systems and can be better used to ensure that any requirements in terms of reasonable adjustments etc. are highlighted to all staff at all stages of cancer treatment pathway. • This should include booking appointments at appropriate time of day, whether support is needed with travel etc. and identifying a preferred recipient for any information to be communicated regarding the patient i.e. medical information or appointments from clinicians/hospitals, to avoid patients and carers missing appointments/being uninformed/finding out about cancer.
Lead organisation	Acute trusts
Resource implications	Low
Timescales for implementation	Medium term (6 – 12 months)
External evidence base/examples of good practice and resources	Reasonable Adjustment Digital Flag training now available - eLearning for healthcare LUHFT have advised that one approach may be to add frailty score to the SCR (Somerset cancer registry) and ensuring that frailty is discussed at MDT (this is already in practice for the Breast Cancer MDT).

Recommendation 7 Assign a named dementia nurse on diagnosis	
Description	<p>One of the key themes highlighted by carers was a lack of consistent support after a dementia diagnosis. This is in contrast to model within cancer services, where patients typically have a named Clinical Nurse Specialist and Cancer Support Worker throughout their treatment journey (although this is not always consistent and funding may be variable depending on Trust).</p> <p>One approach to consider would draw on experiences from the ‘screen and treat’ approach adopted in some psychology services in response to trauma. This model works on the assumption that providing outreach and expertise at an early stage i.e. after diagnosis, can prevent further complexity in the longer term. This model would recommend a highly specialised assessment of need when dual diagnosis is detected (or suspected) by someone with expertise and qualifications in dementia needs as well as awareness of cancer care/physical health needs.</p> <p>Front-loading support after diagnosis and giving patients and carers an opportunity to consider their holistic needs and identify provisions that may meet these needs would have the potential to increase resilience.</p>
Lead organisation	Cheshire and Merseyside ICB and 9 Places
Resource implications	High
Timescales for implementation	Long term (12 months +)
External evidence base/examples of good practice and resources	<p>Recommendations Dementia: assessment, management and support for people living with dementia and their carers Guidance NICE</p> <p>Dementia – discussing and planning support after diagnosis Quick guides to social care topics Social care NICE Communities About NICE</p> <p>Greater Manchester Resilience Hub :: Pennine Care NHS Foundation Trust</p>

Recommendation 8 Mapping exercise of post diagnostic support for dementia to support navigation	
Description	<ul style="list-style-type: none"> • There is inconsistent access to support following a dementia diagnosis as a result of different commissioning and funding arrangements. • Carers are unclear about what is available to them and their loved one. Perception that information given at diagnosis is minimal e.g. leaflets and limited other information and support available in relation to dementia. • Mapping to include information about national resources and helplines to be shared on diagnosis. • Carers report not knowing where they are on the journey with dementia – contrast with structured treatment plans associated with cancer diagnosis. A visual “journey” may help to improve this – it should acknowledge that each person’s journey will be unique but would also be an opportunity to clarify the palliative nature of dementia, which is not always understood. • Alternatively, a piece of work could be undertaken to map of the ability of existing cancer support services to meet the needs of people living with dementia, considering barriers to access and the funding required to ensure equitable access.
Lead organisation	Cheshire and Merseyside ICB and 9 Places
Resource implications	Low
Timescales for implementation	Medium term (6 – 12 months)
External evidence base/examples of good practice and resources	Recommendations Dementia: assessment, management and support for people living with dementia and their carers Guidance NICE Dementia – discussing and planning support after diagnosis Quick guides to social care topics Social care NICE Communities About NICE

Appendices

Appendix 1: Cancer and Dementia Scoping Project - Literature Review

Challenges in the care of a dual diagnosis of cancer and dementia: Themes derived from a review of the literature of primary research conducted in the UK

Themes of the challenges	Papers
Challenges in decision-making in cancer treatment – challenges for patients and carers in making right decision/best interests and capacity, also ethical concern for clinician around treatment safety concerns	Price et al. (2022), Martin et al. (2021), Witham et al (2018), Surr et al. (2020), Farrington et al. (2023), Griffiths et al. (2020)
Challenges for caring responsibilities – lack of support available or offered (from health or social care and only manage one disease) i.e. how to manage at-home treatments, getting time off work for appointments and lengthy treatments	Price et al. (2022), McWilliams et al. (2018), Surr et al. (2020), Courtier et al. (2016)
Challenges in communication from health care professionals and between services – dementia awareness, often services only manage one condition or the other and have a lack of understanding of the other or how they interact i.e. issues in communicating medical information to patients/carers, recognising and recording someone has cognitive impairments – sometimes being ‘bounced around’ the system between health and social care services	Price et al. (2022), Witham et al. (2018), McWilliams et al. (2018), Surr et al. (2020), Courtier et al. (2016), Ashley et al. (2020)
Cancer care pathway not set up for someone with dementia – standardised NHS pathway not meeting individual needs i.e. unclear signage, confusing waiting rooms, missing appointments/appointments not long enough or inflexible times, travel issues and staff unprepared for arrival of dementia patients	Witham et al. (2018), Farrington et al. (2023), Ashley et al. (2020), Martin et al. (2021)

Recommendations derived from a review of the literature of primary research conducted in the UK

Recommendations and improvements	Papers
A need for cancer-dementia specific resources and support for carers and patients – i.e. guidance on decision-making for treatment, support for caregivers involved in at home cancer care, recognising signs of complications/side-effects in dementia patients, travel adjustments, dementia friendly environments	Price et al. (2022), Martin et al. (2021), McWilliams et al. (2018), Courtier et al. (2016), Ashley et al. (2020), Griffiths et al. (2020)
Improve communication from healthcare professionals – i.e. regarding communicating medical terminology in a way that is understandable and allowing for more time during appointments/extra appointments to explain information, written notes from clinics, communication aid tools i.e. pictures	McWilliams et al. (2018), Farrington et al. (2023), Ashley et al. (2020), Griffiths et al. (2020)
Improving inclusion of caregivers and patient in decision-making – i.e. listening to caregivers in clinic who support patient and making clear their input in decision-making	Witham et al. (2017), Farrington et al. (2023), Ashley et al. (2020)
Consistency and communication across services in the care pathway – i.e. consistent person who coordinates care and locations, proper communication and recording of cognitive impairments, assessment of cognitive function at start of care, enquiring about support for caregivers to care at home	Witham et al. (2017), McWilliams et al. (2018), Surr et al. (2020), Courtier et al. (2016), Ashley et al. (2020), Farrington et al. (2023)
Dementia training for oncology staff and vice versa – i.e. training to recognise cognitive impairment, improving awareness and reducing stigma about dementia, capacity, how to speak to dementia patients and considerations when completing examinations, access to practical dementia training	Price et al. (2022), Ashley et al. (2020), Witham et al. (2017), McWilliams et al. (2018), Griffiths et al. (2020)

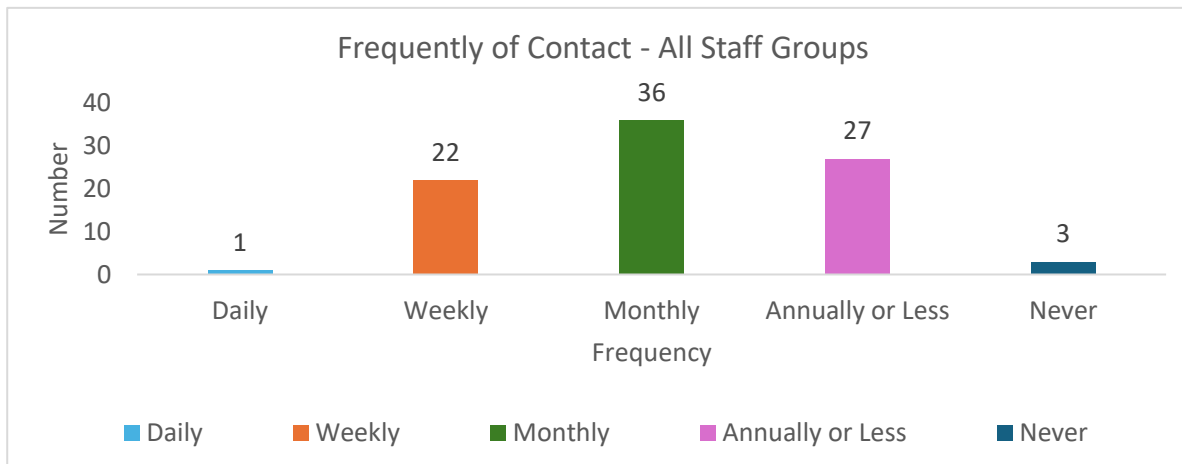
Appendix 2: Cancer and Dementia Scoping Project – Participating Organisations

Name of organisation	Nature of involvement		
	Individual meeting	Stakeholder Workshop	Online Survey
Alzheimer's Society	✓	✓	
Care Home (unspecified)		✓	
Cheshire and Wirral Partnership NHSFT			✓
Christie Hospital NHSFT Manchester	✓		
Clatterbridge Cancer Centre NHSFT	✓		
East Cheshire NHST			
End of Life Partnership	✓	✓	✓
GP Practices	✓		✓
Liverpool Service Users Reference Forum (SURF)	✓	✓	
Liverpool University Hospitals NHSFT	✓	✓	✓
Liverpool University	✓		
Macmillan Information Services		✓	
Marie Curie Hospice	✓		
Merseycare NHSFT			✓
Mid Cheshire Hospitals NHSFT	✓		
Oaklands Care Home	✓		
Orchard Manor Care Home	✓		
St Luke's (Cheshire) Hospice	✓	✓	
Station House Care Home	✓		

Frequency of Contact

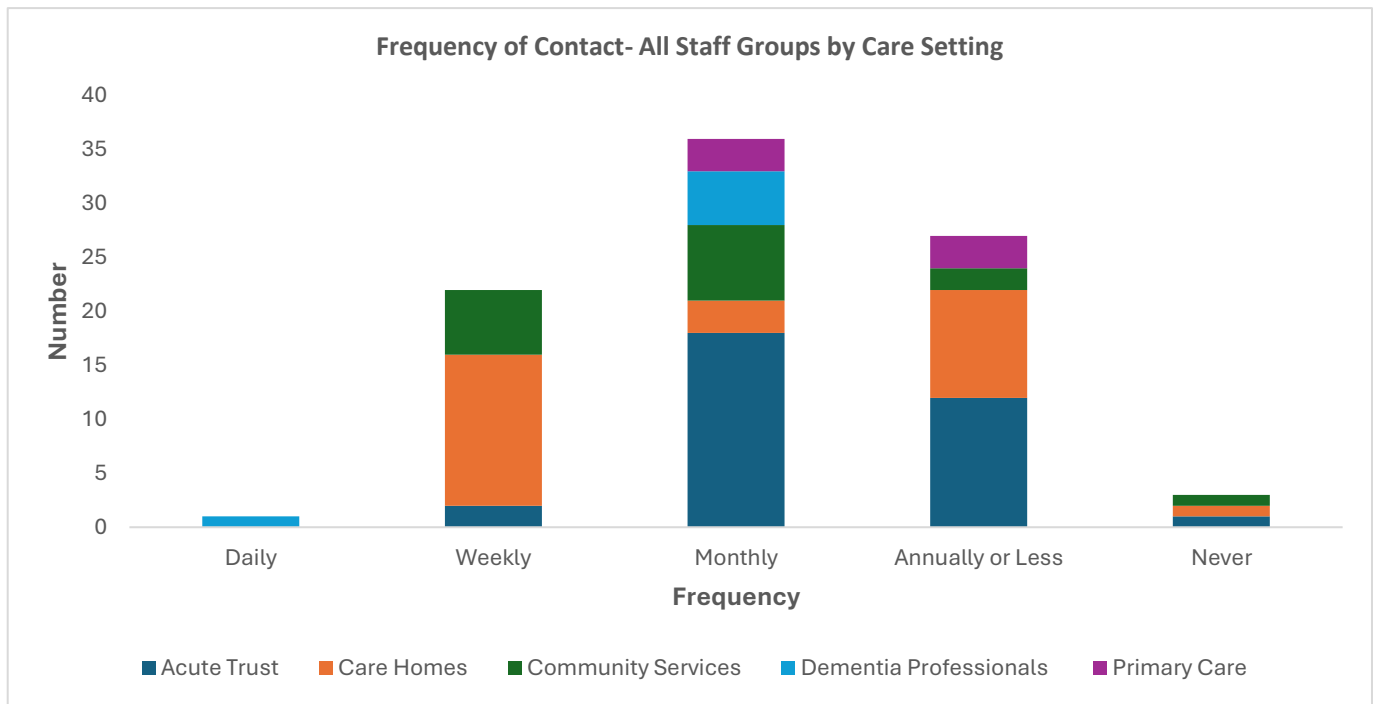
Frequency of Contact Overall All Staff Groups n=89

Frequency of Contact- Grouped Responses	Group Responses (number)
Daily	1
Weekly	22
Monthly	36
Annually or Less	27
Never	3



Frequency of Contact by Staff Group – Summary

	Daily	Weekly	Monthly	Annually or Less	Never
AHP's	0	0	5	4	1
Care Home Manager	0	11	2	8	1
Consultants	0	1	8	0	0
Doctor	0	0	1	3	0
HCA	1	0	1	0	0
Nurse	0	7	2	2	1
Other	0	2	3	6	0
Speciality Nurse	0	1	14	4	0



Frequency of contact by Care Home Type- Count- Summary

Survey Care Homes

Count of Frequency of contact Row Labels	Column Labels				Grand Total
	Annually or less	Monthly	Never	Weekly	
Nursing Care Home	2	2		5	9
Residential Care Home	3		1	2	6
Specialist Dementia Care Home	5	1		7	13
Grand Total	10	3	1	14	28

Confidence in Caring- Averages by Care Setting n=67

Row Labels	Average of Confidence in caring
Acute Trusts	5.9
Care Homes	7.5
Dementia Professionals	6.3
Grand Total	6.6

Confidence in Caring- Averages by Staff Group n=67

Row Labels	Average of Confidence in caring
AHP	5.6
Care Home Manager	7.5
Consultant	5.8
Doctor	7.0
HCA	8.0
Nurse	7.5
Other	5.9
Specialist Nurse	6.3
Grand Total	6.6

Confidence in Communicating- Averages by Care Setting n=67

Row Labels	Average of Confidence in communicating
Acute Trusts	6.0
Care Homes	7.9
Dementia Professionals	7.8
Grand Total	7.0

Confidence in Communicating- Averages by Staff Group n=67

Row Labels	Average of Confidence in communicating
AHP	6.4
Care Home Manager	8.1
Consultant	5.6
Doctor	7.0
HCA	8.0
Nurse	7.5
Other	6.0
Specialist Nurse	6.7
Grand Total	7.0

Acute Priorities – Average Summary Overall and By Staff Group

Staff Group	Average of Access to Admiral nurse or Dementia specialist	Average of Specific Training on Caring for Patients with Cancer and Dementia	Average of Specialist dementia support conducting best interests/capacity assessments	Average of Referral pathways	Average of Designated lead for dual diagnosis
AHP	3.3	1.7	3.0	3.8	3.2
Consultant	1.9	2.9	2.7	3.3	4.3
Doctor	4.0	3.0	1.0	2.0	5.0
Other Specialist	1.8	3.2	2.6	4.4	3.0
Nurse	2.1	2.6	3.1	3.8	3.4
Grand Total	2.3	2.6	2.8	3.7	3.5

Acute Priorities – Count Summary and Rank for All Staff Groups

	Total	Rank
Access to Admiral nurse or Dementia specialist	122	1
Designated lead for dual diagnosis	81	4
Referral pathways	75	5
Specialist dementia support conducting best interests/capacity assessments	104	2
Specific Training on Caring for Patients with Cancer and Dementia	104	2

Count/ Frequencies of Responses	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5
Access to Admiral nurse or Dementia specialist	10	11	5	6	1
Designated lead for dual diagnosis	4	3	7	9	10
Referral pathways	1	5	9	5	13
Specialist dementia support conducting best interests/capacity assessments	8	7	6	6	6
Specific Training on Caring for Patients with Cancer and Dementia	10	7	3	7	3

Acute Priorities- Summary by Staff Group

	AHP	Consultant	Doctor	Other	Specialist Nurse
Access to Admiral nurse or Dementia specialist	4	1	4	1	1
Designated lead for dual diagnosis	3	5	5	3	4
Referral pathways	5	4	2	5	5
Specialist dementia support conducting best interests/capacity assessments	2	2	1	2	3
Specific Training on Caring for Patients with Cancer and Dementia	1	3	3	4	2

Acute Priorities – Average Summary Overall and By Staff Group

Row Labels	Average of Best interest decisions	Average of Communication skills, including the use of communication aids	Average of How a dual diagnosis of cancer and dementia affect assessment and treatment	Average of Mental Capacity Act	Average of Reasonable adjustments for patients and/or Carers	Average of Other
AHP	3.8	2.5	2.8	3.3	2.5	6.0
Consultant	3.7	2.9	2.6	4.3	1.6	5.3
Doctor	1.0	6.0	4.0	5.0	2.0	3.0
Other	3.0	2.0	3.2	4.6	2.2	6.0
Specialist Nurse	3.6	2.6	2.4	3.8	2.6	6.0
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Grand Total	3.5	2.7	2.7	4.0	2.3	5.8

Acute Priorities – Count Summary and Rank for All Staff Groups

	Total	Rank
Best interest decisions	115	4
Communication skills, including the use of communication aids	142	2
How a dual diagnosis of cancer and dementia affect assessment and treatment	142	2
Mental Capacity Act	99	5
Reasonable adjustments for patients and/or Carers	154	1
Other	41	6

Count/ Frequencies of Responses	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5	Rank 6
Best interest decisions	3	5	6	10	9	0
Communication skills, including the use of communication aids	7	8	9	7	1	1
How a dual diagnosis of cancer and dementia affect assessment and treatment	12	6	4	3	7	1
Mental Capacity Act	0	3	7	10	13	0
Reasonable adjustments for patients and/or Carers	10	11	6	3	3	0
Other	1	0	1	0	0	31

Acute Priorities- Summary by Staff Group

	AHP	Consultant	Doctor	Other	Specialist Nurse
Best interest	5	4	1	3	4
Communication skills, including the use of communication aids	1	3	6	1	2
How a dual diagnosis of cancer and dementia affect assessment and treatment	3	2	4	4	1
Mental Capacity Act	4	5	5	5	5
Reasonable adjustments for patients and/or Carers	1	1	2	2	2
Other	6	6	3	6	6

Biggest challenge when working with people with dual diagnosis- Average Summary and Overall by Staff Group

Row Labels	Average of Treatment adherence	Average of Accessing appropriate services	Average of Assessing mental capacity	Average of Great difficulty in assessment	Average of Communication with patients	Average of Distressing impact of medical interventions	Average of Making decisions to treat	Average of Breaking cancer diagnosis	Average of Communication with family/carers
AHP	4.3	7.6	7.6	2.6	4.4	4.1	4.3	4.6	5.6
Consultant	9.0	3.0	2.0	8.0	6.0	4.0	1.0	5.0	7.0
Doctor	7.4	6.9	5.1	5.7	3.2	4.1	4.2	3.8	4.6
HCA	6.0	8.0	7.0	9.0	3.0	4.0	2.0	1.0	5.0
Other	5.6	4.8	5.4	3.8	4.4	4.2	5.0	6.0	5.8
Specialist									
Nurse	6.8	5.9	6.4	4.9	3.1	4.8	4.4	4.3	4.3
Grand Total	6.4	6.3	6.1	4.7	3.6	4.4	4.3	4.4	4.8

Biggest challenge when working with people with dual diagnosis-Count Summary and Rank of All Staff Groups

Count/ Frequencies of Responses	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5	Rank 6	Rank 7	Rank 8	Rank 9
Treatment Adherence	3	2	2	2	3	2	7	10	8
Access to Appropriate Services	4	2	3	2	5	1	2	5	15
Assessing Mental Capacity	3	1	2	2	3	9	9	4	6
Great Difficulty in Assessment	5	5	6	5	1	2	7	7	1
Communication with Patients	10	9	3	2	4	6	2	1	2
Distressing Impact of Medical Interventions	3	5	6	6	6	7	4	2	0
Making Decisions to Treat	4	5	3	10	6	7	1	2	1
Breaking Cancer Diagnosis	5	4	7	4	8	2	6	1	2
Communication with Family/Carers	2	6	7	6	3	3	2	7	3

	Total	Rank
Treatment Adherence	141	9
Access to Appropriate Services	145	8
Assessing Mental Capacity	153	7
Great Difficulty in Assessment	206	5
Communication with Patients	249	1
Distressing Impact of Medical Interventions	219	4
Making Decisions to Treat	223	2
Breaking Cancer Diagnosis	220	3
Communication with Family/Carers	201	6

Biggest challenge when working with people with dual diagnosis- Summary by Staff Group

	AHP	Consultant	Doctors	HCA	Other	Specialist Nurse
Treatment Adherence	3	9	9	6	7	9
Access to Appropriate Services	8	3	8	8	4	7
Assessing Mental Capacity	8	2	6	7	6	8
Great Difficulty in Assessment	1	8	7	9	1	6
Communication with Patients	5	6	1	3	3	1
Distressing Impact of Medical Interventions	2	4	3	4	2	5
Making Decisions to Treat	3	1	4	2	5	4
Breaking Cancer Diagnosis	6	5	2	1	9	2
Communication with Family/Carers	7	7	5	5	8	2

Care Home Priorities-Which would be of most value to you?- Average Summary and Overall by Dementia Professional Group

Row Labels	Average of Access to Macmillan or Cancer Specialist Nurse	Average of Designated lead for dual diagnosis	Average of Specific training	Average of Policy or guidance on decision making	Average of Referral Pathways
AHP	2.5	3.0	4.0	4.0	1.5
Consultant	3.0	2.0	5.0	1.0	4.0
HCA	2.0	4.0	5.0	3.0	1.0
Specialist Nurse	2.5	3.5	3.5	3.5	2.0
Grand Total	2.5	3.2	4.2	3.2	2.0

Care Home Priorities-Which would be of most value to you?- Count Summary and Rank for All Dementia Professional Group

Count/ Frequencies of Responses	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5
Specific Training	0	0	1	3	2
Macmillan or Cancer Specialist Nurse	1	2	2	1	0
Designated Lead for Dual Diagnosis	1	2	0	1	2
Referral Pathways	3	1	1	1	0
Policy or Guidance on Decision Making	1	1	2	0	2

	Total	Rank
Specific Training	11	5
Macmillan or Cancer Specialist Nurse	21	2
Designated Lead for Dual Diagnosis	17	3
Referral Pathways	24	1
Policy or Guidance on Decision Making	17	3

Care Home Priorities-Which would be of most value to you?- Average Summary and Overall by Care Home Group

Row Labels	Average of Specific training	Average of Access to Admiral or Dementia Specialist Nurse	Average of Access to Macmillan or Cancer Specialist Nurse	Average of Designated lead for dual diagnosis	Average of Referral Pathways	Average of Policy or guidance on decision making
Care Home Manager	2.7	3.2	3.0	3.6	4.1	4.7
Nurse	1.0	5.0	6.0	4.0	3.0	2.0
Other	2.3	2.8	2.5	4.5	4.0	5.0
Grand Total	2.5	3.2	3.0	3.8	4.0	4.6

Care Home Priorities-Which would be of most value to you?- Count Summary and Rank for All Care Home Group

Count/ Frequencies of Responses	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5	Rank 6
Specific Training	9	6	2	3	2	2
Access to Admiral or Dementia Specialist Nurse	5	5	4	3	5	2
Macmillan or Cancer Specialist Nurse	4	4	5	10	0	1
Designated Lead for Dual Diagnosis	3	0	9	2	7	3
Referral Pathways	1	5	2	5	7	4
Policy or Guidance on Decision Making	2	3	2	1	3	13

	Total	Rank
Specific Training	107	1
Access to Admiral or Dementia Specialist Nurse	92	3
Macmillan or Cancer Specialist Nurse	95	2
Designated Lead for Dual Diagnosis	77	4
Referral Pathways	72	5
Policy or Guidance on Decision Making	57	6

Care Home Priorities-Which would be of most value to you?- Summary and Rank for all staff from Dementia Professionals Group

	AHP	Consultant	HCA	Specialist Nurse
Specific Training	4	5	5	3
Macmillan or Cancer Specialist Nurse	2	3	2	2
Designated Lead for Dual Diagnosis	3	2	4	3
Referral Pathways	1	4	1	1
Policy or Guidance on Decision Making	4	1	3	3

Care Home Priorities-Which would be of most value to you?- Summary and Rank for all staff from Care Home Group

	Care Home Manager	Nurse	Other
Specific Training	1	1	1
Access to Admiral or Dementia Specialist Nurse	3	5	3
Macmillan or Cancer Specialist Nurse	2	6	2
Designated Lead for Dual Diagnosis	4	4	5
Referral Pathways	5	3	4
Policy or Guidance on Decision Making	6	2	6

Priorities-Which would be of most value to you?- Summary and Rank- Overall Summary

	Care Home Manager	Nurse	Other	AHP	Consultant	HCA	Specialist Nurse
Specific Training	1	1	1	4	5	5	3
Access to Admiral or Dementia Specialist Nurse	3	5	3				
Macmillan or Cancer Specialist Nurse	2	6	2	2	3	2	2
Designated Lead for Dual Diagnosis	4	4	5	3	2	4	3
Referral Pathways	5	3	4	1	4	1	1

Policy or Guidance on Decision Making	6	2	6	4	1	3	3
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Priorities-Which would be of most value to you?-By Care Home Type

Row Labels	Average of Specific training	Average of Access to Admiral or Dementia Specialist Nurse	Average of Access to Macmillan or Cancer Specialist Nurse	Average of Designated lead for dual diagnosis	Average of Referral Pathways	Average of Policy or guidance on decision making
Nursing Care Home	2.2	3.7	3.8	3.0	4.3	4.0
Residential Care Home	2.3	2.0	2.8	3.7	5.0	5.2
Specialist Dementia Care Home	2.8	3.5	2.8	4.3	3.3	4.7
Grand Total	2.5	3.2	3.0	3.8	4.0	4.6

Care Home Priorities- Which areas of training would you find most helpful- Average Summary and Overall by Care Home Group

Row Labels	Average of How to put in place reasonable adjustments for patients/residents/carers	Average of Communication Skills including the use of communication aids	Average of Mental Capacity Act	Average of Best Interest Decisions
Care Home Manager	2.0	1.9	2.7	3.4
Nurse	3.0	2.0	2.0	3.0
Other	2.0	2.0	3.3	2.8
Grand Total	2.1	1.9	2.7	3.3

Care Home Priorities- Which areas of training would you find most helpful- Count Summary and Rank for All Care Home Group

Count/ Frequencies of Responses	Rank 1	Rank 2	Rank 3	Rank 4
How to Put in Place Reasonable Adjustments for Patients/ Residents/Carers	8	13	3	4
Communication Skills including the use of communication aids	15	5	3	5

Mental Capacity Act	4	5	14	5
Best Interest Decisions	1	5	8	14

	Total	Rank
How to Put in Place Reasonable Adjustments for Patients/ Residents/Carers	81	2
Communication Skills including the use of communication aids	86	1
Mental Capacity Act	64	3
Best Interest Decisions	49	4

Care Home Priorities- Which areas of training would you find most helpful- Summary by Staff Group

	Care Home Manager	Nurse	Other
How to Put in Place Reasonable Adjustments for Patients/ Residents/Carers	2	3	1
Communication Skills including the use of communication aids	1	1	1
Mental Capacity Act	3	1	4
Best Interest Decisions	4	3	3

Care Home Priorities- Which areas of training would you find most helpful- Average by Care Home Type

Row Labels	Average of How to put in place reasonable adjustments for patients/residents/carers	Average of Communication Skills including the use of communication aids	Average of Mental Capacity Act	Average of Best Interest Decisions
Nursing Care Home	2.4	1.6	2.7	3.3
Residential Care Home	1.5	2.2	2.8	3.5
Specialist Dementia Care Home	2.2	2.1	2.7	3.1
Grand Total	2.1	1.9	2.7	3.3

Appendix 4: Cancer and Dementia Scoping Project – Expert by Experience Case Study

The following was shared at the Stakeholder Workshop by Sheila Harvey, describing her experiences of caring for her husband Colin. Sheila and Colin's story is shared with her permission, and our thanks.

“Thank you for inviting me to talk about Colin and I's journey through his terminal prostate cancer and later on mixed dementia diagnosis.

Colin was a hard working person who like anybody else enjoyed his hobbies and looking after his family.

His biggest enjoyment was his car, like most men he loved that sometimes more than me.

Colin and I met when he was 17 years old, and I was 16. We got married 3 years later. We have a beautiful daughter and two loving grandchildren.

We received the devastating news of his cancer diagnosis when he was 70 years old. Colin was then later diagnosed with mixed dementia. By the time he received his diagnoses this was mild to moderate and he had to give up his beloved car. The cancer had caused damage to his kidney's leaving him with one partially functioning kidney and the need for Urethral stents.

Colin had in the past suffered with a heart attack was diagnosed with type 2 diabetes and had blood pressure problems meaning he had very complex needs.

Colin and I lived in a three bedroom 2 storey house where I cared for Colin twenty-four hours a day by myself. Colin did not want anyone else to look after him as he said no one could care for him like me. Colin struggled to understand that I had my own health needs and due to the layout of the house and his needs this was a constant struggle.

On the 5th August 2023 Colin was feeling very unwell after having his urethral stents changed. I took him to the hospital but Colin did not like hospitals at the best of times and due to his dementia was unable to understand the importance of the treatment he needed. Due to how busy the hospital was at the time Colin became agitated due to the waiting around and due to his behaviour was sectioned under the mental health act to prevent him from refusing the care he needed and to prevent him leaving the hospital.

This was when the real nightmare part of this journey began for both of us. Colin was put on two different wards over a period of few months. He was in a room on his own and due to his dementia caused him great distress and confusion and only seemed to speed up the symptoms of his dementia. Colin struggled with his coordination and taking medication was a real challenge for him. There were often times where his medication was found on the floor or in his bed as he had been left to take these on his own. When highlighted to staff members these were simply discarded in the bin meaning Colin was not receiving the vital medication he required for his complex needs.

Colin was assigned a social worker, then another. The social workers were often uncontactable and when off sick or on holiday Colin's case was simply left and not passed over. After lots of chasing I was given a list of care homes to ring myself and then visit all whilst trying to visit Colin in hospital seven days a week.

After many phone calls, social services arranged for Colin to be transferred to a dementia care home.

During the time in the care home nobody seemed to understand about Colin's prostate cancer and complex needs let alone how to care for these. I found it very frustrating and tiring trying to get the staff to understand his needs and for these to be met. All the while Colin's symptoms progressed rapidly. Colin after a short time kept trying to escape as he desperately wanted to be at home with myself and our dogs. The home on several occasions had to call the police due to Colin's behaviour and therefore decided that they could not meet his needs and began the process again in trying to find somewhere that would take someone with a dual prognosis.

Colin was then transferred to a dementia unit which deals with all kinds of dementia and alzheimers but sadly they did not have a Doctor qualified in dealing with cancer patients. Meaning Colin was not receiving the care he needed.

This is when I began to question the doctors about why dementia hospitals/units do not have doctor's qualified in cancer care. I pointed out that people can have a dual prognosis and were not a jigsaw puzzle where they could take a piece out of the patient deal with it and put it back and ignore the other complex needs.

After a period of time they too decided that they couldn't do any more for Colin as they did not have the facilities or knowledge to meet his needs and that he therefore yet again needed to be transferred elsewhere.

Colin was transferred yet again to another dementia unit.

Whilst there Colin expressed how he wanted to come home, that he had had enough and that no one was listening to him or myself. Colin throughout his stays in the various wards and units was in a tremendous amount of pain due to the bone metastases. At no point was his pain managed successfully throughout his journey. This caused great distress to Colin, myself and our family.

When I highlighted to a doctor about the extreme pain Colin was suffering with in his legs at the time the doctor admitted that dementia units all over only deal with dementia care and form of cancer care is out of their remit. Following this discussion the doctor called a multi-disciplinary team meeting. At last someone was listening to what I had been trying to explain the whole way through.

During the multi-disciplinary meeting my daughter and I were informed that Colin's cancer had progressed significantly as well as his dementia and that he only had a matter of a month to six weeks to live. It was decided that the unit he was in was not suitable for his needs and he needed to be moved again but that hospice care was not required or available.

Colin was transferred to yet another dementia home on Friday 7th June where he deteriorated at an alarming rate and was in a considerable amount of pain. The home was unprepared for this and his end of life care.

Colin sadly passed away in the early hours of Sunday 16th June – Father's Day after only 9 days in the home.

As you have heard Colin was moved so many times to places unable to meet his needs meaning he was unable to be as pain free and comfortable as possible to enable him to enjoy what time he had left with his family.

Therefore, I am asking everyone in this room to please listen to the patients and their carers. There needs to be better communication between cancer and dementia doctors. There needs to be facilities where patients can receive the care for dual prognosis patients such as cancer and dementia.

We need to act now to ensure no one else has to endure a journey like Colin's and his family. I am here as a voice for patients and their families who have not been heard, with the hope that no one suffers like my beloved Colin again.

Thank you for listening to Colin's journey".