



# **Health Inequalities - Older People**

# **December 2024 Briefing Paper**

This briefing paper is provided by Healthwatch across West Yorkshire and is a summary of the key messages relating to older people that we have heard via West Yorkshire Voice, insight from local Healthwatch across West Yorkshire and from the wealth of existing people's voice reports and insight shared by our partners and local ICB engagement colleagues (see references section at the end of this report). This briefing brings together the key themes from all the above sources relating to older people in West Yorkshire and identifies some key recommendations (see pages 25-26).

During October 2024, a survey was shared via West Yorkshire Voice and across local Healthwatch networks to get a real-time snapshot of current issues for older people. The survey was aimed at older people, their family, friends and carers and professionals. It asked what helps older people stay healthy and well and what gets in the way. It also asked people to share what works well and what doesn't for older people in health and care services.

162 people across West Yorkshire completed the survey. 109 (67%) of these were an older person themselves, 37 (23%) answered as a family member/unpaid carer and 16 (10%) as a professional. There was a spread of responses from all areas (places) across West Yorkshire although as expected responses were predominantly from people identifying as White British and who we assume have digital access due to it being an online survey.

To compliment this, as well as drawing on existing insight from different communities, outreach conversations were led by West Yorkshire Voice to further understand the experiences of people and communities at greatest risk of health inequalities. We would like to thank our West Yorkshire Voice partners Bradford Talking Media, Asha Neighbourhood project (Leeds), Spectrum Community Health and Belle Isle Church (Wakefield), Upper Valley Primary Care Network (Calderdale), The Brunswick HIV support group (Kirklees) and Out Together (Leeds). Their feedback can be found in a 'Community testimonies' section towards the end of this briefing paper.

# 1. What factors help older people to feel healthy and well and what gets in the way?

### 1.1 Healthy living

Keeping active, eating healthily, and reducing or stopping smoking or drinking, were all frequently mentioned as things that helped people to stay well. Some carers and professionals mentioned health and mobility issues as factors affecting older people's ability to shop for food, prepare meals and eat well. Walking, gardening, cycling and fitness classes were the most frequently mentioned physical activities. People benefit from organised community activities and said that they would like to see more affordable and age-appropriate fitness and activity groups in their areas.

# 1.2 Being socially connected

People told us that connection, love and support from family, friends, neighbours and their wider community were crucial for their mental and emotional wellbeing.

"I go into town on the free bus and talk to people about what is going on in the world and not on the news I spend time studying so keep my mind active and help people in any way I can."

Older age is also a time that people can feel more lonely or socially isolated. People highlighted factors such as retirement, bereavement, long term conditions and disabilities, as well as reduced support networks due to children being busy with their own lives or ageing without children.

"Nobody is able to help me get up and go for a walk. I'm bored and have no one to talk to when my husband is asleep. I have the same routine every day, wake up, have breakfast, watch TV, play games on my tablet and nap, have lunch and repeat. I have no physical motivation or mental stimulation."

Community and faith groups are frequently mentioned as a key support for older people in enabling them to socialise, get out and about, and act as a gateway to accessing other support. Some people mentioned that there weren't always suitable groups near to where they lived, whilst others said that they wanted a more diverse range or greater frequency of activities.

"I attend lunch groups to keep me social... they have different activities for mental health and physical activities."

Several people also mentioned volunteer befriending services as being important for people who are housebound.

"It is possible to feel lonely in a crowded room... Not everyone enjoys participating in groups - some people prefer 1:1 support."

# 1.3 Public spaces – Green, social and cultural spaces

Many older people said that the following are important to help them stay well:

- Getting outside to access safe, clean and accessible green spaces.
- Accessing cultural and social spaces such as museums, galleries, theatres and cafes.
- Accessible public toilets and seating.
- To feel welcome in spaces they visit.

#### 1.4 Transport and travel

In the Leeds City Council, Director of Public Health Annual Report 2023<sup>1</sup>, 21% of people surveyed reported that changes to the transport system would better enable them to stay happy and healthy. Many respondents to our recent survey also told us about transport issues being one of the key things that gets in the way of them feeling well.

"Being dependent on public transport and its problems. Difficulty getting around the city and beyond, difficulty getting to see family and friends, and to hospitals. Not having fitness/sports facilities or swimming pool within walking distance. Too time consuming to get anywhere that does have facilities. Too stressful. Psychological impact of all the above; feeling excluded."

General themes around travel and transport from across all insight sources were:

- Limited public transport options can be a barrier to people doing activities and attending health appointments. Age UK identified that it is the people with the worst health and on the lowest incomes who struggle most to travel to health services<sup>2</sup>.
- Older people who can't drive or walk long distances, those with disabilities and/or from low-income areas, and people whose first language isn't English are more likely to face barriers to travelling.

- Older people are sometimes reliant on family and friends to support with transport. This can be an issue if people are ageing without children or children have other caring or work responsibilities.
- Concessionary bus passes were helpful to support people ageing well.
   However, people want to be able to use them before 9.30am, for example to get to early health appointments.
- There is a variation in bus service frequency and routes across West
  Yorkshire. Public transport can be a particular problem in rural areas
  where there is also more likely to be an ageing population with long bus
  routes to get to essential health services and a lack of routes serving
  smaller villages.
- Older people who are unable to get transport or live in rural areas with poor transport links are often reliant on getting expensive taxis if they aren't aware of or are ineligible for patient transport.

"Wetherby has a terrible bus service, so it is impossible to arrange appointments or attend mental health support in Leeds and with no access to long term mental health support in Wetherby I am left to cope with my Bipolar alone. This is not fair."

"It's cheaper to fly to Ibiza for £49 than get an accessible taxi from Hebden Bridge to the hospital."

 In North Yorkshire, having a car was reported as being essential to get to health services. Without it, many people shared that they would have either struggled or not known where to get support with transport.

"If you haven't got friends and family and older people that's stopped driving like, you know, most of my friends have stopped driving, you're a bit snookered, you really are snookered aren't you." <sup>3</sup>

- People want locations where they get support to be local and accessible, and where possible, at the same place each time. People said that community groups need to be within half a mile of their homes for them to be likely to access them. In a recent consultation, "being cared for as close to home as possible" was the most important factor for older people when thinking about mental health services4.
- Many older people have said that being able to access information or have an informal chat in the community would be an easier, more accessible way for people to start having conversations around mental health. For example, a library, church or community building.
- Age friendly paths and routes and availability of accessible taxis were also mentioned as factors that enabled people to age well.

"Taxis are not always accessible, and drivers are not always patient or sympathetic. Drivers need to be trained around age, disability and dementia - this surely would be good for business too. Having an impatient driver has at times, made mum stay home and lose confidence."

# 1.5 Long-term health conditions

Many people told us that poor health, long-term conditions and general lack of energy and stamina got in the way of them feeling mentally and physically healthy. They explained that it affected their ability to do the things they wanted to do to keep them well such as getting out the house, socialising and being active.

"Feeling isolated whilst struggling with a progressive long-term condition can be very lonely and frightening place to be."

#### 1.6 Mental health and wellbeing

There are certain factors that are more likely to affect older people's mental health such as poor health (as mentioned above), bereavements and retirement.

"My husband died 10 years ago, and I live alone. In spirit I am very independent and have in the past attended trips and events for isolated people, and will again if I get suitable treatment for my knee. But I do get depressed and lonely when I am so inactive."

People told us about ways they look after their mental health such as:

- Physical activities and sports.
- Keeping mentally active with activities and hobbies such as reading, crafts or playing music.
- Getting enough sleep.
- Spending time with family and friends.
- Having a pet and walking their dog.
- Practicing their religion or doing practices such as mindfulness and meditation.

"Conversation/interaction is crucial for the elderly's mental health. this was very apparent during Covid with my grandmother. Her health deteriorated substantially because of this."

People also told us that their mental states - feeling lonely, unmotivated, lacking in energy and feeling isolated - were a significant factor that got in the way of them staying healthy. We also heard about the impact of the seasons and bad weather on older people's wellbeing and ability and confidence to get out.

"Dark nights, change in season - more lonely at this time of year. Spend more time inside."

There is still significant stigma for many older people around talking about mental health who, for example, many still talk about "breakdowns". This is often even more entrenched in some culturally diverse communities where people told us there are also issues around mistrust of services.

Many older people don't want to ask for help and feel they "just need to get on with it". Men, in particular, are often reluctant to get support, but may be more likely to attend 'men only' support groups with an activity focus (e.g. woodworking).

More work needs to be done with older people - especially those from diverse communities - to build their vocabulary and confidence to talk about how they feel as well as trust of services. There is also a potential role for professionals to adapt their language and approaches to meet people where they are in terms of understanding of their own health.

#### 1.7 Financial wellbeing

The cost-of-living is having an impact on people, particularly those on low income. There is increased usage of food banks, and some older people told us they are worried about the rising costs of food and keeping their home warm, which can negatively impact on their health.

Other themes that came up were:

Concerns about paying rent and bills.

"Without winter fuel allowance this year my relative is beginning to stress about how they will manage and are worried they will be an extra burden on NHS staff if they fall ill because of it."

- Being able to access free or low-cost activities to keep healthy.
- Not being able to afford to do social activities which impacts on mental health.
- People feeling they must continue working after pension age due to money worries, despite not being in good health.

"Having to work full time even though I am 65- I cannot afford to retire or cut my hours... Not having enough money to improve my house, pay my mortgage off."

#### 1.8 Employment, volunteering and having a sense of purpose.

Work or volunteering, as well as informal acts of helping others, was important for many people to help them stay happy and healthy as they get older.

"My Mum has dementia and lives in a care home. She responds well to and is stimulated by helping others and feeling useful. We are often sent photos of her 'helping' to clean and it might just be muscle memory but she's singing along while she wipes a table or helps putting decorations up."

Some mentioned the vital social element and sense of purpose that work gives them. People also shared that flexible employment, health support at work and the ability to have a good work-life balance were also important.

# 1.9 Housing

Older people have shared, in relation to housing, that it's important for them to:

• Stay in their own home and live independently for as long as possible

- Feel confident and supported about housing options (including finances) when the time comes to leave home.
- Have enough affordable, accessible and age-friendly housing available to them.

# 2. Unpaid carers

For many older people, having someone that provides unpaid care for them is an integral part of what helps to keep them well. As well as providing love, support and companionship, unpaid carers play a vital role for older people in providing practical help, advocacy and help to navigate the system. They also often play a role in helping the person they are caring for to understand information and communicate, especially where English is not the first language and interpreting is required.

Older people are also more likely to be carers themselves. Nationally, between 55 and 64 is the most common age for people to have caring responsibilities. Older people are also more likely to be dealing with their own health conditions alongside increased caring responsibilities.

From the State of Unpaid Caring in Leeds report 2023<sup>5</sup> the top three concerns for carers were identified as:

 Negative impact on carers' own health and wellbeing needs, including their social lives and relationships. Healthwatch Kirklees and Calderdale identified that this was a particular issue for older male carers<sup>6</sup>.

"As a carer I cannot easily get to appointments as I would have no one to care for my wife. I'd have to bring her, so it makes it harder. There isn't someone to sit with her either. If I used a paid sitter, it would cost money... and how easily can they be booked last minute?"

Too many carers feel they are not always listened to or included as part
of the team planning care for the person they care for. Many carers
also share that they often don't receive the information they need to
support the person they care for effectively, don't know what services
are available or are unable to find care and support services in their
area that meets their needs.

"Ward rounds take place when family are not present, and my elderly relative is hard of hearing and has poor understanding of health language so is not able to pass on information."

Unpaid carers are also more likely to experience poverty than those who aren't carers because of caring responsibilities impacting their ability to work.

# 3. Accessing health and care services

Regular health checks, vaccinations, "visiting the GP when I need to", access to specialist helplines for long term conditions, follow-up support, and proactive communication from healthcare providers were all frequently mentioned as factors in helping people to stay well. People also mentioned taking their medication and attending other support groups.

"I attended a six-week course for back problems and have blood pressure checks at my local pharmacy."

# 3.1 Access to General Practice (GP)

In our survey and outreach, we asked people what worked well for them and what didn't when accessing health and care services. Many respondents highlighted that timely and easy access to healthcare services,

particularly their GP was a key factor in helping them to stay well. Many people reported difficulties getting a GP appointment and this causing frustration, anxiety, mistrust and lack of confidence in the system.

"Not being able to see a GP when I feel I need to. The GP triage system and messages being sent via PATCHS which I don't use - too many layers to get through to a GP. Not worth the effort. Lost confidence in GP services and Primary Care. Might as well wait until feeling even worse and just go to A&E."

#### 3.2 Digital access and exclusion

Some older people have good digital literacy and told us that online services such as the NHS App and PATCHS were helpful for them to manage their appointments and prescriptions.

"I like using e-forms and systems when contacting my NHS GP as it saves hanging on to a telephone and means I can request most things without having to go into the surgery."

However, it should not be assumed that all older people have digital access. People aged 65+ are the biggest proportion of adults who do not use the internet and age is one of the biggest indicators of who is digitally excluded. This is exacerbated by other factors such as income, education levels, disabilities, sensory impairments and when people's first language isn't English. Many older people tell us that trying to learn how to do things digitally can be daunting, overwhelming and frustrating. The cost of technology can also be a barrier - if people don't own their own digital equipment, they are less likely to keep using it regularly.

From reviewing existing insight, we know that many older people:

 Find it difficult to book GP appointments, access health information and order repeat prescriptions digitally.

"My relative can't access online services so paper leaflets would be preferable to inform of services/useful contact numbers."

- Feel nervous or distrustful of technology and are concerned about the move towards online platforms in many aspects of their lives.
- Feel that digital or online services are something they don't need or want to use.

"My mother-in-law is 78 and is not digitally aware, she has no idea how to access PATCHES at her GP and does not want to learn now."

- Prefer in person appointments and support groups. Some older people shared concerns about the robustness of virtual or phone assessments and how they feel less comfortable discussing symptoms over the phone. This was particularly the case for older people with more complex health needs and long-term conditions.
- An unintended consequence of 'digital by default' can be increasing social isolation for older people as interactions that were previously in person move online.
- Rely on family members or community groups for digital access, which
  can be disempowering, reduces people's independence and feel
  uncomfortable, if it means disclosing private health matters.

"Hospital appointments are sent by text which my dad misses as he doesn't know how to access them. He struggles to sort these independently... which takes away his independence and sets him up to fail."

 Don't have as much access to information about support services if they aren't online.

- Use digital in some aspects of their lives (e.g. video calling family) but not in others. They may own a smartphone but are only able to use a fraction of the functionality.
- Feel that they are being left behind by the rapid move to digital.

"When new systems are introduced, they should have a trial period with the age range that could be using it. Some new systems are or could be good ideas ... if you were asked to give your opinions on what works and where they don't."

#### 3.3 Communication needs

Unpaid carers told us that it was really important that health and care professionals took the time to explain things simply and clearly to older people. They also stressed the importance of written communication being easy to understand. It should be remembered that 11 is the average reading age for people in the UK. Some older people do not read at all, and we still need to be able to communicate with them.

Older people are also more likely to be Deaf, Hard of Hearing or have visual impairments and their communication needs must be taken into account. Phone consultations are especially difficult for people with hearing impairments and documents may need to be in larger print for some older people with visual impairments.

"When appointments are cancelled because of no interpreters. When the BSL interpreter cancelled on the day, and I don't understand my appointment. When nurses refuse to remove their masks so I cannot lipread. When the doctor was rude and spoke to my daughter instead of me. When

appointments letters say call to book or cancel. I can't call. They don't give any other option."

We often hear from people with disabilities and sensory impairments that services are not always adhering to the requirements of the Accessible Information Standard, resulting in frustration and difficulties with getting fair access to services.

"As a person with autism, I find it very stressful to use the telephone to get a doctor's appointment due to the long wait. Even concentrating on filling in the online PATCHS form leaves me exhausted so I often give up. I feel some healthcare staff are not interested in knowing if a person has a brain that functions differently to "the norm" and more training needs to be given so that staff understand that not everyone is the same."

Deaf people have also shared experiences of where they have tried to contact services using an interpreter and being blocked because staff incorrectly say they cannot speak with the interpreter because of GDPR.

Older people whose first language isn't English told us that it can be difficult to access services, communicate with health professionals and get the information they need. This is more likely to be a barrier for older people who are first generation immigrants. People mentioned not being consistently offered interpreters, issues with interpreters not speaking the appropriate dialect, and information not always being available in different languages. We talked to a group of South Asian women, many of whom told us that they couldn't read. This is also an issue in other communities such as the Roma who don't have a written language. These issues are often compounded by digital exclusion which further marginalises people. Some people told us that they have to rely on younger family members to help them with appointments, as well as interpret and advocate for them.

However, they also said that family members didn't always have enough time to support them due to work and childcare responsibilities.

#### 3.4 Waiting times

People frequently talked about the long waits for referrals, access to services and treatment as a factor preventing them keeping well and having a negative impact on their health.

"The thing that hinders her staying well and healthy is when services take a long time to respond to requests from the staff at the home for a reassessment of mum and her medication. She has vascular dementia, so it is an ever-changing debilitating condition. Two to three weeks is a long time for someone who is unwell and needs help. Especially from a 'rapid' access team."

This included access to social care assessments.

"Social care is non-existent with waits of over three months to be allocated a social worker."

We heard about the worry caused when people aren't kept up to date during long wait times.

"Not being informed of the waiting time is so worrying... maybe the referral hasn't been made or I've got lost in the system."

# 3.5 Compassionate care

Positive experiences of healthcare professionals who were attentive, respectful, and understanding were frequently mentioned in our survey responses. Many appreciated when staff took the time to listen and engage with them personally and support them to feel calm and reassured.

"The nurses and reception at the MacMillan centre, Calderdale Royal, offered a first-class service for Chemotherapy patients, where everyone in their care was made to feel special and loved. They were always cheerful and always had something nice or comical to say to help you through the treatment and to make you feel good about yourself."

Some respondents however reported being treated as less competent because of their age resulting in them feeling infantilised or dismissed by healthcare staff, negatively impacting their experience.

"Health professionals often speak to her like a child, or, worse still, don't speak to her but speak about her directly to me as though she is not there or not capable of having her own opinions. This too affects her confidence."

#### 3.6 Coordination

Older people (like the rest of the population) want services that provide continuity and are well coordinated. They want services and departments to talk to one another and have the person receiving care at the centre.

"My Mum gets much better health care and attention now that she lives in residential care. The staff know her and monitor her health... They have the authority to contact her GP and mental health professionals. The GP also does the equivalent of a ward round at the home.... Us working with the home staff provides shared care and a more holistic approach for Mum."

Older people and the people who support them expressed frustration when services weren't joined up, sometimes leading to confusion and delays.

"As an 83 yar old she is does not understand new and different services.

Unrealistic expectations from GP practice staff - expecting her to go to surgery to take samples, not joining up appointments, not working with the

patient and family to provide a seamless service. Everything is arranged to suit the practice and not the patient. Not having continuity by the same professional - for an elderly patient this is a big, big issue."

Several people suggested that having a 'one stop shop' for appointments, support and information would be really helpful for older people.

"Not every older person has an advocate. I think it would be great if there could be a service that meets at and looks at all the needs a person might be experiencing under one roof and at one appointment, be it health/social/mental health. This would enable older persons to engage with all services required in a timely fashion, reducing numerous appointments, which can be confusing and difficult to access."

#### 3.7 Cultural needs

Older people and their carers told us that they weren't always asked about their cultural needs and preferences when accessing care and how this impacted on their experiences. This includes the LGBTQIA+ community.

"When we attended appointments, health professionals would always assume I was Tom's carer or another relative, never his husband. I wish they had just asked, "How are you connected to Tom?"

This is often an issue for people accessing social care services, where people may need assistance to make food, socialise, access activities, and practice their religion. Having a same gender worker for personal care or someone who can speak the same language for example may be very important culturally. People told us that it is also really helpful for staff to involve unpaid carers where appropriate to help them understand how to best meet their loved one's cultural preferences.

"My mother has dementia [and is] Punjabi speaking. Notes were left on walls for her food alerts, still food that contained egg and wasn't halal. The meal orders my mother couldn't contribute to due to dementia, language barrier, lack of choice and understanding of meals offered."

People from culturally diverse communities with dementia may also benefit from reminiscence activities that are different from cultural norms. People told us that they don't expect people to know everything about their cultures, they just wanted to be asked and for people to avoid making assumptions.

"Services shouldn't assume that Asian families will always care for their loved ones. They need to understand that the person receiving care might not want to be cared for by their family members."

People also talked about how there is work to be done to address low uptake of services by culturally diverse communities, such as uptake of intermediate care and reablement services in Kirklees and Calderdale<sup>7</sup>.

"Show what happens and how the family can also be involved in care alongside services so there is no stigma to my family for accepting help other than family members."

Some people talked about their language and cultural needs not being met as directly contributing to mistrust of services because they felt unheard and misunderstood.

# 3.8 Knowing what is out there

Many older people don't have the information they need about health and care services available to them. This is more likely to be the case if they are not online or don't have family or community support.

"It is hard unless you know how to navigate around the services and systems where you need the support from. If I was not caring for them, they will never be able to find out about how to get the support to staying well."

We also found where English was not an older person's first language, this created an additional barrier. For example, in the Healthwatch Calderdale and Kirklees work on intermediate care and reablement<sup>7</sup>, they found that there was very low awareness of these services amongst the Asian British Pakistani, Asian British Indian, and Black British African people they spoke to<sup>6</sup>.

Healthwatch Wakefield recently did some engagement with veterans (predominantly aged 55+)8, a community which is more at risk of physical and mental health issues and facing challenges in accessing appropriate healthcare services. Their report identified very low awareness of specialist veteran health services amongst older veterans, leaving many feeling alone with a lack of ongoing support.

#### 3.9 Dementia

Carers and professionals told us that that in their experience there was often poor access to early diagnosis for dementia, a lack of support whilst living with dementia and inappropriate care during hospital stays which could lead to declines in general health, wellbeing and cognitive function.

"Once diagnosed there is nothing. You're just left. No medication, no pathway, no follow up, no treatment plan, no guidance. You might get some information to follow up yourself. This is inadequate when dealing with a diagnosis that has a devastating impact and only gets worse. Everything is left to the carers."

Carers shared that hospital staff were not always skilled in providing care to or communicating with people with dementia.

"Admissions wards do not work for elderly patients as they get moved several times during their stay and can add to their confusion and be very upsetting for them."

People reported that the current very long waits in A&E were often very distressing for people with dementia and their carers.

"I had to stay with her 24+ hours as she was stripping off and trying to walk around and had no-one to sit with her. Another woman in her eighties was having to do the same with her husband. I was in my 50's and exhausted but she must have been. No A&E is equipped for dementia patients and as it is the largest killer they need to get equipped."

People often tell us that there are not enough community and social activities for people with more advanced dementia. We have sometimes also found this to be the case during our Healthwatch Enter and View visits to care homes, where the activities on offer are not always appropriate or stimulating for people with more advanced dementia.

Often, the concerns Healthwatch hears about neglect in hospitals and care homes relate to people with dementia. Although not specifically relating to people with dementia, the following came from a professional working in complaints in West Yorkshire:

"We have had many complaints about the standard of care whilst an inpatient. Examples of older patients not assisted to the toilet when they are continent, lack of assistance with nutrition and hydration and oral care, placed in side-rooms with no access to TV or radio, call buzzers placed out of reach. Patients not mobilised or got dressed, mouth care not carried out,

property going missing. Patients feeling frightened when there has been poor communication, and they don't understand what is happening".

Carers of people with dementia tell us that they do not always feel that they are included in conversations about their loved one's health and care, even when they have power of attorney.

#### 4. Important role of third sector in staying well

Some older people, particularly those in low-income areas without strong family support, have shared that third sector organisations or partnership projects such as the Neighbourhood Networks and Enhance in Leeds<sup>9,10</sup> play a key role in helping them to stay well. They often provide easy local access to holistic, culturally appropriate support that people feel comfortable accessing. Support provided can include wellbeing and activity groups, general information and advice, opportunities to learn new skills and make social connections, transport and volunteering. Organisations often also provide support in navigating the health and care system, understanding health information and sorting out appointments.

"[I] have met lots of new friends. I feel better health wise now...before I didn't go out and was really struggling with my mental health - now I am in a much better place... I have a more positive outlook – I wouldn't have come out of my house without it – it changed my life."

People told us they had been impacted by reduced activities and services as a result of funding cuts to local community groups. Some mentioned that transport to groups and activities was no longer provided.

"Access to social activities, clubs, events, exercise and wellbeing sessions are key - this needs to be funded so that older people with limited income

can also access them. This includes transport - some older people no longer drive, some with limited mobility will find public transport difficult and the only option is a taxi which can be too expensive."

# 5. Health and care system and older people

Many respondents to our survey commented that they felt that the healthcare system often fails to recognize the unique needs of older adults. Some people told us how this made them feel neglected. This was also echoed by professionals working with older people and family carers who responded to our survey.

"Patients are becoming more vulnerable and isolated as there are not the services there to support housebound patients. It is so upsetting to see this. There is no one to ensure they are managing their long-term health conditions and/or prevent hospitalisation. Focus is more on acute issues and a holistic assessment is not carried out and followed through to address other issues for them."

"Dad has had numerous falls and has been told to go sit and wait in A&E to get checked over. He has terrible pain and is not able to sit for long periods. He finds this situation too stressful and does not visit hospital post-falls. The GP visiting at home is much better, but this is only if it is available on the day."

# 6. Death and dying

Between 2023 and 2024, four reports have been published by Healthwatch (Leeds, Kirklees, Calderdale and Healthwatch across West Yorkshire) and the

Director of Public Health in Kirklees on people's experience of end-of-life care across Kirklees, Leeds, and West Yorkshire as a whole<sup>11,12,13,14</sup>.

They collectively highlight what people, communities and carers say is important for them in terms of end-of-life care along with associated recommendations. In summary, the most common themes raised by people were:

- The importance of compassionate person-centred care.
- The need for effective pain and symptom management, enabling people to be as comfortable as possible.
- People want better, honest and more frequent conversations with staff about what to expect before, during and after death.
- People valued the opportunity to discuss end of life wishes as early as possible before death.
- Good co-ordination of services and receiving clear accessible information contributed to positive experiences of end-of-life care and knowing what to do after someone dies.
- Caring for someone at home at the end of life has an impact on whole families.
- Insufficient availability of bereavement support can leave people, and particularly spouses and men feeling isolated.

The reports also highlight inequalities in people's experience of death and dying, with particular groups identified as more likely to have a poorer experience of death and dying:

- People with long term conditions
- People experiencing homelessness
- People with serious mental health illness
- People with addiction issues

- People in contact with the justice system
- People with learning disabilities or living in poverty,
- People from culturally diverse communities
- People who identify as LGBTQ+
- People living in rural areas.
- Unpaid carers

For more detailed information on the inequalities experienced by the above groups and recommendations for how these could be addressed, please see the referenced reports.

# **Key Messages and recommendations**

There are many recommendations that we could make from the broad themes covered by this report, but we have chosen to limit it to six. These are based on the themes coming through most strongly from the people of West Yorkshire, particularly focusing on what we were hearing from those more at risk of health inequalities.

- 1. With the fast-paced move to digital, we must recognise that a large proportion of older people in West Yorkshire will experience digital exclusion and poorer access to services, unless we make sure that non-digital options are always made available. This covers everything from booking appointments, receiving communications and accessing health information and records.
- 2. Recognise that good transport and easily accessible local services are a key factor in older people keeping well. We recommend that West Yorkshire Combined Authority works with local authorities to increase accessible and safe travel for older people to support independence,

- reduce isolation, and make it easier to attend activities and health appointments. People also need to be made aware of travel options available to them.
- 3. Older age is a time that people can feel more lonely or socially isolated. We need to prioritise free and low-cost activities and inclusive spaces for older people to gather and socialise. The third sector play a key role in this and is a lifeline for many older people with community organisations also acting as an important gateway to accessing other support. Cutting funding to the third sector potentially has a big impact older people's health and wellbeing.
- 4. The communication needs of older people should always be considered and acted on when designing, delivering and promoting services. This includes specific requirements of the Accessible Information Standard, as well as more generally ensuring that all communication is clear, simple, and accessible and available to people without digital access. Face-to-face communication and information in paper format was particularly important to older people. Routine access to interpreters also needs to be improved.
- 5. Be curious about people's needs, both at an individual and system level and with a focus on health inequalities. This should include people's access, cultural and health needs as well as proactively listening to unpaid carers who are often important advocates for the people they care for. Build systems, services and behaviours around people's particular needs so that they work and are more likely to be accessed.
- 6. Older people want to be treated with respect by health and care staff and involved in decisions about their care. Like everyone else, they

value compassionate care and don't want to be infantilised or treated as less competent due to their age or health conditions.

# **West Yorkshire Community Testimonies**

#### Bradford Talking Media learning disability group

Bradford Talking Media aims to make information accessible for everyone. It is committed to enabling any person who cannot access the written word to access to any information they may need or want to enable them to live a full and happy life that they are in control of.

#### What gets in the way of staying healthy and well?

- Loneliness and feeling isolated
- Dementia/ health issues or conditions.
- Waiting for responsible family members to check up on them.

#### What works well when using health and care services?

 Pharmacy first - more accessible than GPs – giving out medications and signposting.

# What doesn't work well when using health and care services?

- Difficult to get GP appointments due to difficulty getting through on the phone or not being confident with booking online appointments – even with some assistance, people just don't understand what to do.
- The 8am ring up rush means people are having to wait day after day to try and get an appointment.
- Modality GP services in Bradford if you do manage to get an appointment it might be at a GP that's far from home and must make travel arrangements.
- Triaging through receptionists means they're not being given the opportunity to get support after being asked about symptoms.
- Having to wait for things like medication etc for a long time is frustrating

#### Asha Neighbourhood Project, Leeds

Based in Beeston, the Asha Neighbourhood Project aims to improve the lives of all women and children living in South Leeds by giving them a wider understanding of their rights, opportunities and services available in order for them to live a healthier, happier and more productive life.

#### What things help you to keep healthy and well?

- Diet some women said they try to eat well and some told us they
  must take extra care of their diet because of health conditions such
  as diabetes.
- Physical activity and attending exercise classes organised by Asha once a week-people mentioned wanting more available exercise classes to attend and funding for Asha to run them. Asha used to support women to access swimming sessions the women miss this and want this to be incorporated again. Hamara used to provide transport to the group activities, but this was discontinued during the pandemic.

# What makes it difficult to stay healthy/what prevents you from staying healthy?

- Cannot resist eating traditional foods even though they can be unhealthy with lots of oil.
- Difficulties travelling to fitness classes or social groups etc.
- Women who are 'stuck at home' as they do not have support to go
  out. Asha provides a lot of support to one woman who lives next
  door to Asha, but staff highlighted that this would not be possible for
  anyone in a similar position who is not so close by.
- Long term health conditions make going to exercise classes difficult.

 Some women mentioned 'mood swings' caused by health conditions that affects their motivated to keep fit.

## What works well when using health and care services?

- Some said doctors were available when they needed them.
- Good experiences of physiotherapy.

### What doesn't work well when using health and care services?

#### Language barriers

- Language barriers when trying to speak to doctors and medical
  professionals about health issues. One woman mentioned that there
  is a nurse who checks on her at home, but because the
  nurse/interpreter can't speak her dialect, it can make it difficult to
  communicate and get appropriate support.
- Mixed experience of being offered interpreters when attending appointments. Sometimes this happens and sometimes it doesn't.
- Difficulties related to interpreters not speaking the same dialect as
  the person (e.g. various different dialects of Punjabi). This has led to
  misunderstandings from both the interpreter and the person seeking
  healthcare which can impact treatment.
- Women say they are sometimes told not to bring family members
  along to the appointments for interpreting (this is the preferred
  option for many), but the alternative is being given interpreters who
  do not fully understand them due to different dialects.

# Dependence on family, carers and third sector for support:

 A lot of the women live alone and have difficulties getting to doctors' appointments. Their families have moved away to other parts of Leeds or further afield and have their own work and

- childcare responsibilities. They can find it hard to take time out of work to support them with travel to and interpreting at their appointments as there is usually no paid carers leave.
- Reliance on Asha to advocate for them, for example help them to understand letters, call health services and arrange patient transport on their behalf.
- Asha used to get funding to take the women to hospital appointments, which worked well, however, they no longer get the funding.
- Lack of awareness of transport help available to get to health appointments.

#### Access to support:

- Difficulty getting a GP appointment sometimes staying on the phone for a long time to not end up getting an appointment.
- Feeling that in the past appointments were easier to access, however, now they feel the doctors question them a lot about the way they are feeling, and they don't feel believed.
- Difficulties getting medication from the pharmacy who don't have interpreting support in place.
- Women told us they find it physically and mentally draining sitting at A&E for long periods of time.
- Some women said they prefer getting medical advice abroad as the process is a lot quicker.
- Frustration at seeing different doctors each time they get resulting in them having to explain the same thing several times.

# Communication and being listened to:

• Some mentioned how they feel they are not heard by doctors.

- Women didn't like telephone consultations and questioned "How
  can the doctor see their health over the phone?". Sometimes miss
  the phone calls because the call is scheduled for a window, or the
  doctors don't give them enough time to pick up the call.
- Majority of the women do not know how to read/write English which affects their ability to understand information sent out. Some said they got letters from the hospital in their language but cannot read them.
- They get confused with the different options on automated phone calls - for example when they ring there are lots of options (press 1 for this etc)
- Most not able to use or access digital technologies.
- They mainly rely on doctors to give them the information they need or their families to get the information and pass it onto them.
   Sometimes they find out information from groups such as the ones run at Asha.

# Belle Isle Church Warm Food Drop-in, Wakefield

Offers food, conversation, and support to anyone who comes along. Also offers support with any benefit and housing issues.

One person shared the experiences of their mother who had dementia:

- Delay in dementia diagnosis resulting in delay in getting appropriate care and support.
- Lack of specialist dementia ward at Pinderfields.
- Wasn't assessed as needing a care home place but home care was inadequate as lack of overnight care resulted in continence needs not being met.

#### Upper Valley Primary Care Network, Calderdale

# (Personalised Care Team Lead, Ageing Well Nurse -frailty and social prescriber).

#### What factors help older age adults stay healthy and well?

- Previously managing their wellbeing well.
- Good mindset and habits.
- Social support and adequate finances.

#### What factors get in the way of older age adults staying healthy and well?

- · Managing their weight.
- Social isolation and anxiety meaning they fear social activities and appointments.
- Lack of transport. Access to groups i.e. disabled access in buildings.
- Leaving the house if access to property is hazardous.
- Bereaved patients can struggle to feel motivated to engage and care for themselves after a loss.
- Not educated well on what to do for physical health if they have a
  health condition such as arthritis or back pain tend to slow down and
  stop which impacts their mobility further.

# What do older people tell you works well in health and care services?

- Neighbourhood networks are very close knit and support the work across the region.
- Upper Calder Valley are good at supporting one another in the community due to the rurality.
- Proactive calls and outreach to people to offer support for 'ageing well' – not everyone would access this of their own accord.

- When people feel listened to.
- Having diverse staff to support different communities and building relationships with those who are less likely to access services.
- For GP appointments, there seems to be an improved level of home visits in the area.
- Being able to speak to a real person, someone who can navigate computers for them. Easy read information. Consistency of who they speak to and knowing who does what and how they work together.

# What do older people tell you doesn't work well when using health and care services?

- Online services, only being able to email or complete forms online. Lack of face-to-face support.
- Todmorden health centre it is a large health centre but doesn't have many local services running there and could be used more for this.
- Some people are put off attending support and appointments due to needing to travel long distances e.g. in Calder and Ryburn.
- Meals on wheels can't get beyond a certain area. This means services
  like the ageing well team are providing additional support in the form of
  care packages.
- Lots of people have long term health conditions to manage alongside the normal challenges of looking after their health while ageing.
- Calderdale Community Transport exists for people but there aren't enough volunteer drivers.
- They have worked with people who struggle to book patient transport,
   and the hospitals and GPs are often not supporting with this process.

#### The Brunswick HIV support group, Kirklees

The Brunswick Centre offers a range of services and projects to various communities in Calderdale and Kirklees including activities for people who are HIV positive.

#### What things help keep you healthy and well?

- Good support from the Brunswick Centre including walking group, allotment group and one-to-one counselling. It can be hard to talk about HIV in other spaces and there is a comfort in knowing others are the same as you.
- It is good to get out and about and meet new people, socialise and be
  active. Some people are on their own at home or have moved to the
  area recently and said it can be hard to find ways to meet people.
   Also, can learn from each other about what support there is.
- Having a community like this group is good for helping with other areas
  of health and care such as helping each other out with lifts to the
  hospital.

# What things get in the way of you being healthy and well?

- Not enough funding for community/support groups there need to be more.
- Taking early retirement after lockdown and suffering with bad anxiety and panic attacks. Found it difficult to know what to do next and find ways to get out and about and use their time.
- It is hard to find bungalows as a form of accessible housing. This led to
  one person having to move to an area outside of their existing
  community.

# What works well when using health and care services?

- Good HIV support at Huddersfield Royal as it is easy to get to, there is a small team, and they give you lots of care. The signage is also sensitive, and the department has a name which doesn't make it obvious it is for HIV which is important for people to feel comfortable.
- Being listened to is important for good support.
- Two people shared a positive experience of having Cognitive Behavioural Therapy (CBT) for anxiety and depression via IAPT.

# **Out Together**

Out Together is a charity that champions social inclusion for older LGBTQIA+ people by hosting regular activities and events in Yorkshire.

#### What works well when using health and care services?

- Some people prefer digital approaches to booking appointments and managing health and care needs. E.g. someone with Parkinsons told us it is increasingly difficult to use the phone and booking an appointment via the NHS App/SystemOne works well for them: "I like to have access in a way that is comfortable for me, and this way I can go back and look at the record."
- Another person said they feel confident with technology, and it avoided being in the phone queue. However, they were worried about other older members of the group who find technology difficult.
- Someone shared a positive experience of accessing their GP, getting a
  last-minute appointment for an eye problem, being sent to A&E where
  they were seen quickly and given a follow up appointment.

#### What doesn't work well when using health and care services?

- Digital appointments someone shared how they kept missing
  notifications on PATCHS/NHS App. They would prefer phone calls or text
  messages as they don't like using technology. Another person said
  they had faced the barrier of needing to get their surgery to approve
  using an app to book appointments or order prescriptions. This had
  stopped them trying to use digital services as they were unsure how to
  go about this.
- Someone shared that their son was recently diagnosed with ADHD and this has made them want to get assessed as well due to having similar symptoms. They found out that referrals have closed in Leeds and heard about Right to Choose but isn't sure how to go about it.
- Hospital waiting times "Ever since covid, its (the health system) not kept to that arrangement, you're just waiting and waiting. Why is it taking so long to get over the covid effect."

#### References

<sup>1</sup> Leeds City Council, Director of Public Health Annual Report 2023: Ageing Well: Our Lives In Leeds, 2023. <a href="https://www.leeds.gov.uk/public-health/director-of-public-health-annual-report-2023">https://www.leeds.gov.uk/public-health-annual-report-2023</a>

<sup>2</sup> Age UK, 2015, The Future of Transport in an Ageing Society.

<a href="https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/active-communities/rb">https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/active-communities/rb</a> june 15 the future of transport in an ageing society.pdf

<sup>3</sup> Healthwatch North Yorkshire and Institute for Social justice, 2023, Rural Health Inequalities.

https://www.healthwatchnorthyorkshire.co.uk/report/2023-11-01/rurality-and-healthcare-barriers

- <sup>4</sup> NHS Arden and Greater East Midlands CSU NHS Midlands and Lancashire CSU, 2024, Older people's mental health inpatient services consultation <a href="https://www.southwestyorkshire.nhs.uk/wp-content/uploads/2024/07/Older-peoples-mental-health-inpatient-services-consultation-report-v3.0.pdf">https://www.southwestyorkshire.nhs.uk/wp-content/uploads/2024/07/Older-peoples-mental-health-inpatient-services-consultation-report-v3.0.pdf</a>
- <sup>5</sup> Carers Leeds, 2023, The State of Unpaid Caring in Leeds <a href="https://www.carersleeds.org.uk/thestateofunpaidcaringinleeds2023">https://www.carersleeds.org.uk/thestateofunpaidcaringinleeds2023</a>
- <sup>6</sup> Healthwatch Kirklees and Calderdale, 2023, Let's hear it for men's health and wellbeing. <a href="https://healthwatchkirklees.co.uk/report/mens-calderdale-report/">https://healthwatchkirklees.co.uk/report/mens-calderdale-report/</a>
- <sup>7</sup> Healthwatch Kirklees and Calderdale, 2024, Ethnically diverse people's experience of reablement and intermediate care services.

  <a href="https://healthwatchkirklees.co.uk/report/ethnically-diverse-peoples-experiences-of-reablement-and-intermediate-care-services/">https://healthwatchkirklees.co.uk/report/ethnically-diverse-peoples-experiences-of-reablement-and-intermediate-care-services/</a>
- 8 Healthwatch Wakefield, 2024, Serving those who have served.

  https://www.healthwatchwakefield.co.uk/wpcontent/uploads/2024/07/Healthwatch-Wakefield-Veterans-Report-Servingthose-who-have-served.pdf
- <sup>9</sup> Dr Sarah Alden, 2024, Summary of the Enhance evaluation findings for year two. <a href="https://www.opforum.org.uk/resources/summary-of-the-enhance-evaluation-findings-for-year-two/">https://www.opforum.org.uk/resources/summary-of-the-enhance-evaluation-findings-for-year-two/</a>
- <sup>10</sup> Centre for Ageing Better, 2022, Leeds Neighbourhood Networks Report <a href="https://ageing-better.org.uk/resources/leeds-neighbourhood-network-phase-two">https://ageing-better.org.uk/resources/leeds-neighbourhood-network-phase-two</a>

- 11 Healthwatch in West Yorkshire, 2023, People's experience of end-of-life care in West Yorkshire. <a href="https://www.healthwatchbradford.co.uk/report/2024-02-09/peoples-experiences-end-life-care-west-yorkshire">https://www.healthwatchbradford.co.uk/report/2024-02-09/peoples-experiences-end-life-care-west-yorkshire</a>
- <sup>12</sup> Healthwatch Kirklees, 2023, Dying in Kirklees what matters? https://healthwatchkirklees.co.uk/report/dying-matters-kirklees-healthwatch-report-and-supportive-information/
- <sup>13</sup> Healthwatch Leeds, 2023, Bereaved carers survey about end-of-life care in Leeds. <a href="https://healthwatchleeds.co.uk/reports-recommendations/2023/bereaved-carers-2023/">https://healthwatchleeds.co.uk/reports-recommendations/2023/bereaved-carers-2023/</a>
- <sup>14</sup> Kirklees Council, Director of Public Health annual report 2023 to 2024: Inequalities in the experience of death and dying.
  <a href="https://www.kirklees.gov.uk/beta/director-of-public-health-annual-report/2023-2024/index.aspx">https://www.kirklees.gov.uk/beta/director-of-public-health-annual-report/2023-2024/index.aspx</a>

# Other reports and presentations that fed into this report

Health for all, 2023, Report on the existing knowledge of experiences of people over the age of 55 of mental health services.

Healthwatch Kirklees and Calderdale, 2024, Let's hear it for women's health and wellbeing. <a href="https://www.healthwatchcalderdale.co.uk/report/lets-hear-it-for-womens-health-calderdale-local-report/">https://www.healthwatchcalderdale.co.uk/report/lets-hear-it-for-womens-health-calderdale-local-report/</a>

Healthwatch Leeds, 2024, Repeat prescriptions community check in,. <a href="https://healthwatchleeds.co.uk/reports-recommendations/2024/repeat-prescriptions/">https://healthwatchleeds.co.uk/reports-recommendations/2024/repeat-prescriptions/</a>

QA Research, 2022, State of Ageing in leeds: Qualitative Engagement for Age Friendly Leeds. <a href="https://ageing-better.org.uk/sites/default/files/2022-03/State of Ageing in Leeds Report qual.pdf">https://ageing-better.org.uk/sites/default/files/2022-03/State of Ageing in Leeds Report qual.pdf</a>

Healthwatch Leeds, 2022, Changing Home Care Engagement Panel.

<a href="https://healthwatchleeds.co.uk/reports-recommendations/2023/home-care-2022/">https://healthwatchleeds.co.uk/reports-recommendations/2023/home-care-2022/</a>

Kirklees Council, West Yorkshire Integrated Care Board and World Health Organisation presentation, 2024, 'Older people are telling us what an Age Friendly society and community looks like in Kirklees'

Mind in Bradford, 2024, engagement around older people's mental health with South Asian communities (Title to be confirmed - not yet published).

Leeds Older People's Forum, Age Friendly Leeds & Leeds City Council, 2024, Food Security and Older People. <a href="https://www.opforum.org.uk/wp-content/uploads/2024/11/Food-Security-Older-People.pdf">https://www.opforum.org.uk/wp-content/uploads/2024/11/Food-Security-Older-People.pdf</a>