**1. Introduction**

1.1 This paper is one of a suite of documents used as part of our Community Integrated Risk Management planning process. A number of groups have been identified as potentially being at greater risk of fire or are potentially not accessing services such as Safe and Well visits. There are a range of equal access cases presented which require focus and additional resources to evaluate further whether this is the case. In the public consultation we will ask people in our communities to work with us to understand further any issues from their perspectives. We also want to work in partnership to re-design services or access pathways where needed.

**2. Further understanding of Equal Access**

2.1 As a public service focused on excellent service to our customers, we need to ensure equality of access to our services for every person and those in temporary residence or transit through the County.

2.2 We know though our fire investigation and Operational Assurance processes that some people are more likely to have a fire and they include those who are living with Dementia, mobility issues, and mental health issues.

2.3 There are however other communities/people who aren’t necessarily showing as being at higher risk of a fire but they may not be accessing our services such as safe and well visits or reporting fires because of other barriers which may be language, perceived prejudice and other societal factors/historical discrimination.

2.4 Equality of access means actively seeking to engage people who may be unaware or choosing not to access services from us and other public sector providers.

2.5 We need to work to reduce fire risk and other life risk across all the people and that needs different approaches. Within our equality of access approach, we also need to:

* 2.6 Identify the all the communities and customers that make up the FRS area.
* 2.7 Consider how we and improve the provision Fire Rescue Service (FRS) services as well as access to employment opportunities with FRS to include all our communities across a range of variables including ethnicity, disability, gender, sexual orientation, religion or belief and age.
* 2.8 Learn from and enhance good practice identified through equality monitoring.
* 2.9 Use the results of equality monitoring to mitigate any adverse impact of our services and employment processes on groups within our diverse communities.
* 2.10 Eliminate any unlawful discrimination identified through equality monitoring.
* 2.11 Promote good community relations.
* 2.12 Use appropriate engagement techniques including social marketing to inform and focus on behaviours to help customers adopt safer ways of living.

2.13 Data, academic evidence and case studies have informed our people impact assessments, these now need refining by contributions and insights from people living with Dementia and support groups and communities e.g. charities and grass roots engagement.

**3. Contextual Background**

3.1 All FRSs have pledged to the [Dementia friends programme](https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/dementia-friends) as part of the [Prime Minister’s dementia challenge](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf). As part of our commitment as allies we want to keep pushing to reduce fire risk for people living with dementia so they can stay longer in their homes. By becoming Dementia Friends our workforce will develop a greater understanding of what it is like to live with dementia and help us to improve and tailor our services.

3.2 UK defines dementia as a major neurocognitive disorder that affects memory and thinking and interferes with daily life**.** Dementia is not a normal part of ageing. According to the Alzheimer’s Society over 40,000 people under the age of 65 have early onset dementia, caused by diseases which result in a loss of nerve cells in the brain.

3.3 Dementia isan umbrella term for a range of progressive conditions with diverse underlying pathological issues which become worse over time. The five most common types of dementia are:

* 3.4 [Alzheimer’s disease](https://www.nhs.uk/conditions/alzheimers-disease/).
* 3.5 [Vascular dementia](https://www.nhs.uk/conditions/vascular-dementia/).
* 3.6 [Dementia with Lewy bodies](https://www.nhs.uk/conditions/dementia-with-lewy-bodies/).
* 3.7 [Frontotemporal dementia](https://www.nhs.uk/conditions/frontotemporal-dementia/).
* 3.8 [Mixed dementia](https://www.alzheimers.org.uk/blog/what-is-mixed-dementia).

3.9 Alzheimer’s is a physical disease in which abnormal structures build up inside the brain. The communication between nerve cells becomes disrupted and the cells begin to die. Early symptoms may appear as memory loss, inability to recall recent events, or the right words, and eventually becoming disorientated.

3.10 Vascular dementia is a condition caused by the lack of blood that carries oxygen and nutrients to a part of the brain. Dementia with Lewy bodies is a progressive dementia that results from protein deposits in nerve cells of brain. Frontotemporal dementia is an uncommon type of dementia that causes problems with behavior and language.

Mixed dementia is a mix of more than one type of dementia.

3.11 Dementia has no known cure but there are some treatments that can help manage the condition. It is common in people who are aged 60 and older, and more women than men are diagnosed with the condition. A family history of frontotemporal dementia may increase the likelihood of other family members becoming developing dementia in later life.

3.12 In the UK, 62% of people with dementia are female and 38% are male. This is likely to be a consequence of the fact that women live longer than men, and age is the biggest known risk factor for the condition.

3.13 More than 20,000 dementia cases in UK are diagnosed each year. Figures released by the NHS reveal a 71% rise in the number of people diagnosed with dementia. As of December 2019, NHS data showed 19,556 people had been diagnosed with the disease compared to 11,437 in 2014.

3.14 There is greater prevalence of dementia among Black and South Asian ethnic groups. These groups of people are more prone to risk factors such as cardiovascular disease, hypertension and diabetes, which increase the risk of dementia and contribute to increased prevalence.

3.15 Already an estimated 21 million people in England have a close friend or family member living with dementia. Dementia is the most feared health condition, more feared than any other major disease, including cancer and diabetes for people over the age of 55 according to a survey by [Alzheimer’s Research UK](https://www.alzheimersresearchuk.org/).

3.16 In respect of fire protection, according to the Alzheimer’s society, the main fire risks in the home for someone living with dementia are those that are related to a person’s past role or actions. This includes using appliances in the home incorrectly, or an incident or accident caused by memory impairment. Smoking and alcohol use are also a particular risk for people with dementia because they may forget that they are holding a cigarette and burn themselves or leave it lit and unattended thereby running the risk of causing a fire. Smoking in bed is a particular risk. Additional risk may arise form person’s inability to react to a fire alarm due to decision making difficulty. People with dementia may have difficulty making some decisions but will be able to make other decisions themselves. For example, a person might not be able to make decisions about their medical treatment, but could make decisions about what they eat, or which television programmes to watch. Different people with dementia will be able to make different decisions. As the dementia progresses the decisions an individual will be able to make will change.

3.17 As a result of these figures, dementia is recognised in [The NHS 5 Year Forward View](https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf) in relation to getting serious about prevention, supporting those with dementia, supporting carers and developing new care models.

**4. Why should we be concerned about equality of access for those people living with dementia in an FRS context?**

4.1 This is not just an issue to be considered in relation to the services FRSs provide, but also the partners and agencies we work alongside.

4.2 As part of the Prime Minister’s dementia challenge, FRSs across England were invited to sign up to a pledge to improve the safety of those with dementia.  We want those with dementia to live a safe and happy life by remaining in their own homes as long as possible.  Not only does this improve the quality of life for people living with dementia but it will also reduce the financial impact on the families and organisations supporting people.

4.3 The Prime Minister’s challenge on dementia built on the achievements of the National Dementia Strategy and linked well with the CFOA document [Ageing Safely - Protecting an ageing population from the risk of fire in the home](http://www.cfoa.org.uk/12282).  During 2012/13, **people over the age of 60 were 10 times more likely to die in a fire** than those aged 17-24.  Research has also shown that impairment, disability and dementia are a substantial factor in increasing someone’s risk of injury or death from fire in the home.

4.4 Many FRSs are members of the [Dementia Action Alliance](https://www.dementiaaction.org.uk/). We need to update our national data on fires related to dementia after the next census.

4.5 Prevention activity is about ensuring we design in equality access for people who may not be able to access services such as Safe and Well visits, and who rely on carers, family and other networks to support them make best decisions. To live independently in their home for as long as possible with appropriate care, protected when discharged home from hospital, and provided with specialist fire safety equipment to reduce fire risks and incidents in the home.

**5. Dementia communities that require focus from an FRS perspective**

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| **5.1 Older age-related dementia and mobility**5.2 The risk of developing dementia is around 3.5 times higher in frail older adults than in non-frail peers according to a study published by [UCL (University College London) Scientific Reports](https://www.ucl.ac.uk/news/2017/nov/higher-risk-dementia-among-frail-older-adults).5.3 The study found frailty affects around 17% of older adults in England and that those who were frail at the start of the study had a greatly increased risk of developing dementia over the next ten years. The findings also revealed that adults on the verge of becoming frail already had almost twice the risk of developing dementia.5.4 Frailty is a complex but common condition of older age, which is defined by a combination of problems with mobility, physical disability, poor general health, eyesight, and hearing, as well as chronic problems like cardiovascular diseases and depression. NHS England defines frailty as ‘a loss of resilience’ that means people living with frailty do not bounce back quickly after a physical or mental illness.5.5 Older people unable to access rehabilitation services because of their dementia diagnosis are impacted considerably by potentially becoming trapped in a vicious cycle of becoming frail, falling, and then spending time in hospital only to become frailer or discharged home without the adequate care support in place. Frailty increases falls and dementia and hospital stays increase the pressures on acute services. Consideration needs to be given for safety in the home to avoid:* 5.6 incidents and accidents e.g. cooking incidents and trips and falls,
* 5.7 the potential for self-neglect,
* 5.8 hoarding,
* 5.9 becoming a victim of scams, and
* 5.10 previous patterns of behavior repeating, including smoking and alcohol use.
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| **Actions:** | * 5.11 Continue to work with interagency referrals, particularly when the customer is unable to do this for themselves.
* 5.12 Community engagement, raising the profile through campaigns of the free Safe and Well service.
* 5.13 Continued work with Dementia Action Alliance/Dementia Friendly Community groups to strengthen joint agency work.
* 5.14 Internal awareness raising with staff, and promotion of the national dementia awareness week.
* 5.15 Continued delivery of the Dementia Friends and Champions training.
* 5.16 Developing dementia awareness raising through induction processes.
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| **6. Women and dementia*** 6.1 Care givers or care receivers.
* 6.2 Changes in family dynamics, impact on work and finances.
* 6.3 Loss of dependency or independency according to whether care giving or care receiving.
* 6.4 Potential consideration to same sex female couples given that dementia is more prevalent in women.

6.5 The Alzheimer’s Association International Conference reported that women are more likely to be affected by specific genetic mutations that can cause dementia. Dementia has become an urgent global health crisis that is only set to worsen.6.6 Women are disproportionately affected by dementia. The World Health Organisation list dementia as one of the top ten causes of death for women and it is the top cause of death for females in the UK. 6.7 Women are more at risk of dementia than men, with women making up to 65% of people who currently have the condition in the UK.6.8 Research shows that women not only face a greater prevalence of the condition but also fulfil the majority of care support roles. Internationally women account for two in three providers of dementia care support. Cultural norms, particularly in lower and middle-income countries often determine that a mother, daughter or daughter-in-law should assume the role of family care giver. These unpaid care responsibilities mean many women are forced to sacrifice job opportunities either by reducing their hours or ceasing work altogether. This will increase the possibility of financial hardship and food and fuel poverty. |
| **Actions:** | * 6.9 Continued linkage with care navigator networks and interagency referrals.
* 6.10 Understanding financial impact from service providers such as [Age UK](https://www.ageuk.org.uk/) and [Department for Work and Pensions](https://www.gov.uk/government/organisations/department-for-work-pensions) in terms of [benefits](https://www.gov.uk/browse/benefits) available, and application routes to financial assistance.
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| **7. Learning disabilities and dementia** * 7.1 They are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis.
* 7.2 They may experience a more rapid progression of dementia, although this can be complicated by difficulty or delay in diagnosis.
* 7.3 They may have already learned different ways to communicate (e.g. more non-verbal communication if their disability affects speech).
* 7.4 They could already be receiving social care in the family home or be in a supported living environment where they are given help to allow them to live independently.
* 7.5 They will need specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis as dementia progresses.

7.6 Memory loss and learning disability combined with the probability of additional mental health conditions all compound the dementia diagnosis. Additional considerations need to be given around anxiety and depression, possibly leading to isolation, self-harming or self-neglect. 7.7 Dementia generally affects people with learning disabilities in similar ways to people without learning disabilities. However, there are some important differences. People with a learning disability and particularly those with [Down's syndrome](https://www.nhs.uk/conditions/downs-syndrome/) are at greater risk of developing dementia at a younger age. This group of people often show different symptoms in the early stages of dementia and are more likely to have other physical health conditions which are not always well managed. |
| **Actions:** | * 7.8 Closer linkage with disability networks to share best practice and ensure learning opportunities are developed.
* 7.9 Understanding referral routes which are dementia specific, and those which are mental health specific including community support networks.
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| **8. Early onset of dementia*** 8.1 Changes in family dynamics and caring responsibilities.
* 8.2 Possibility that young carers adopt the responsibility.
* 8.3 Early onset dementia can impact upon work and family life, loss of connections can cause the person living with dementia to become isolated and depressed.
* 8.4 Financial difficulties may contribute to additional burdens on family life.

8.5 Younger people with dementia experience a range of challenges which are often different to those of older people. Younger people are less likely to experience memory loss as one of their early symptoms, and may experience problems with behavior, vision or language first. They are also likely to have varied aspects to their lives that will be affected in different ways by dementia. This includes:* 8.6 Their relationships, including with their children.
* 8.7 Their finances.
* 8.8 Employment (if they’re working) and daily activities.
* 8.9 Driving.
* 8.10 Their hobbies and interests.

8.11 All of these can make it hard for a younger person to adjust to a diagnosis. Dementia can also be harder for younger people because it usually comes at a time in their life when it is least expected. 8.12 Dementia at any age can have a big impact on relationships. However, for younger people there are particular challenges that can affect their relationships with partners, family, friends and work colleagues. Dementia at any age can lead to questions about how roles in relationships will change. For younger people with dementia this can be more challenging due to their commitments. They may have a mortgage, young children and household duties they share with a partner or friend.8.13 A partner or children of the person with dementia may end up providing more and more care for the person over time. This can be difficult to adapt to and can lead to a big change in family relations with children becoming young care givers. |
| **Actions:** | * 8.14 All the same considerations as already mentioned in the section above, with additional thoughts to be given to the impact on young carers. This should include the support for them through community and voluntary networks.
* 8.15 For the customer living with early onset dementia, exploring links and referral pathways which can be made with neurology services soon after a dementia diagnosis.
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| **9. People from a Black, Asian and Ethnic minority background and dementia*** 9.1 Impact of caring for a family member outside of community provided services.
* 9.2 Late diagnosis or care that doesn’t meet the cultural needs and beliefs of the customer.
* 9.3 Inability to work as a care giver could cause financial hardship.

9.4 There is some evidence from dementia charities that there are lower levels of awareness of problems such as depression and dementia within Black, Asian and Ethnic minority communities. Some older people and their families have problems accessing help from services due to stigma attached. There is insufficient evidence on whether integrated or separate services are more effective, but there is a need for more culturally appropriate and sensitive services. 9.5 In 2011 there were 25,000 people with dementia from Black, Asian and Ethnic minority groups in England and Wales (Alzheimer's Society, 2012). This number is expected to double to 50,000 by 2026 and rise to over 172,000 by 2051. This is nearly a seven-fold increase in 40 years, compared to just over a two-fold increase in the numbers of people with dementia across the whole UK population in the same time period.9.6 Despite this the [All Party Parliamentary Group on Dementia](https://www.alzheimers.org.uk/about-us/policy-and-influencing/all-party-parliamentary-group-dementia) has found that people from Black, Asian and Ethnic minority backgrounds are less likely to receive a diagnosis or support. This is thought to be partly due to cultural beliefs around mental health, and ill-informed thoughts that the condition may be a punishment that the individual or family must bear. This then becomes a hidden diagnosis causing further burden to the care giver as they cope without specialist support services. |
| **Actions:** | * 9.7 Develop referral routes with local and national providers.
* 9.8 First consideration needs to be given to building a safe network with advocates and trusted sources from within ethnically diverse groups for the proposals to refer and signpost to be successful.
* 9.9 Additionally, consider how people living with dementia and who are alone could be identified and supported.
* 9.10 Age UK networks could be utilised and other referral pathways which support veterans, and older people living independently could be explored.
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| **People from the LGBT communities with dementia**The UK has over 1 million older LGBT people ([ONS, 2017](https://www.gov.uk/government/publications/national-lgbt-survey-summary-report/national-lgbt-survey-summary-report)) several reports including the 2016 [National Care Forum Report](https://www.nationalcareforum.org.uk/wp-content/uploads/2019/10/Dementia-care-and-LGBT-communities.pdf) have identified that whilst LGBT people with dementia share some of the same experiences as heterosexual people living with dementia, there will be many issues that are not the same. LGBT people with dementia have specific health needs along with the usual care and support issues as everyone else as they age. For example:* People worrying about being forced “back into the closet” in later life because of the attitudes of care staff.
* LGBT older people being more likely to be estranged from relatives and lacking family support, which makes formal care even more important than it is for their heterosexual peers.
* Some people lose their inhibitions due to dementia, while others who have previously come out feel unable to be open about their sexuality or transgender status.
* The anguish and confusion caused by dementia being exacerbated as LGBT people with the condition struggle to deal with negative perceptions of their sexuality or gender in society.
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| **Actions:** | * Education and training of staff in respect of sexual and gender identity in relation to dementia this might involve encouraging the use of gender neutral pronouns and an understanding that people might have a wide support network involving those who are not conventional family members.
* Promoting diversity such as showing same-sex couples in marketing materials may increase feelings of acceptance within the community.
* Using partnership approaches with community groups to reach those that perhaps would not automatically connect with accessing our services using a person-centred approach, encouraging staff to regard LGBT people with dementia as “people first”.
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**10. Key areas of focus to improve sector evaluation and engagement for people living with dementia and their carers:**

* 10.1 Monitoring equality outcomes for customers.
* 10.2 Ensuring Emergency Services continue to work towards becoming dementia friendly organisations.
* 10.3 Seeking qualitative evidence to support how we continue to provide the best service and fire safety measures for people with dementia.
* 10.4 Pledging work to seek personal commitment to the safe and well advice.
* 10.5 Asking charities and other public sector providers to help survey for needs and outcome measures.
* 10.6 Having a clear inclusion strategy which supports people with memory impairments to live safer in their homes.
* 10.7 Continue training and awareness events for staff to improve their understanding of supporting people living with dementia.
* 10.8 Adopt the person-centred approach to Safe and Well/Home Fire Safety visits so that customers living with dementia have their needs met.
* 10.9 Capture when a customer has dementia at the time of an operational incident through IRS which can be fed-into the national IRS project.
* 10.10 Engage and involve a family member/carer as early as possible when a fire incident is identified due to dementia. This extends to collaborating with a wide range of care navigator networks or link workers.
* 10.11 Continue to support customers from diverse and under-represented groups with dementia in a way which meets their cultural needs and reflected in the wider Safe and Well offer.

10.12 Develop further research with Health and Universities to understand what evidence is available nationally in relation to fire incidents caused by people with dementia.

**11. Useful websites and publications**

Alzheimer’s Society Emergency Services Guide 2020: [Dementia-friendly emergency services | Alzheimer's Society (alzheimers.org.uk)](https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/resources-organisations/emergency-services)

Alzheimer’s Society Key publications about dementia: <https://www.alzheimers.org.uk/get-support/publications-factsheets/publications-dementia>

World Alzheimer Report 2012: <https://www.alzint.org/resource/world-alzheimer-report-2012/>

Dementia Profile: <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>

Things you can still do with dementia – but didn’t know you could: <https://www.dementiauk.org/?msclkid=592fd6ec929e197ec94689bb16aaea15&utm_source=bing&utm_medium=cpc&utm_campaign=Dementia%20UK%20%5BTier%201%5D&utm_term=dementia%20uk&utm_content=Dementia%20UK>

Alzheimer’s Society Dementia-friendly emergency services: <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/resources-organisations/dementia-friendly-emergency-services>

GOV.UK - Writing about ethnicity: <https://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

[Writing about ethnicity - GOV.UK (ethnicity-facts-figures.service.gov.uk)](https://www.ethnicity-facts-figures.service.gov.uk/style-guide/writing-about-ethnicity)

Bournemouth University Dementia Institute: [Fire Safety Innovations for People Affected by Dementia](http://www.cfoa.org.uk/download/63722)

**Local Government Association** [**Beyond fighting fires:** The role of the fire and rescue service in improving the public’s health](http://www.cfoa.org.uk/download/60044)

**NFCC:** [**Fire Safety in Specialised Housing**](http://www.cfoa.org.uk/download/67392)

**12. References**

Dementia UK – What is dementia: <https://www.dementiauk.org/get-support/diagnosis-and-next-steps/what-is-dementia/>

Alzheimer’s Society – Keeping safe: fire, cooking and kitchens: <https://www.alzheimers.org.uk/get-support/staying-independent/fire-risk-cooking-kitchens>

Public Health England - Health matters: midlife approaches to reduce dementia risk: <https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

University College London – Dementia: <https://www.ucl.ac.uk/dementia/>

Alzheimer’s Society - Why is dementia different for women?: **Error! Hyperlink reference not valid.**<https://www.alzheimers.org.uk/blog/women-and-dementia-overlooked-majority>

Alzheimer’s Society - Learning disabilities and dementia: <https://www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia>

Alzheimer’s Society - Living with dementia as a younger person:<https://www.alzheimers.org.uk/about-dementia/types-dementia/particular-issues-faced-younger-people-dementia>

Alzheimer’s Society - Alzheimer's Society's view on demography: <https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/demography>

Social Care Institute for Excellence: <https://www.scie.org.uk/publications/guides/guide03/minority/>