The East of England Citizens’ Senate <https://www.eoecitizenssenate.org/> weekly drop-ins have been focusing on frailty: prevention, treatment, cure. We have also considered frailty through the lens of hospices: palliative and end of life care, prevention and compassionate communities.

We used the following questions to direct the conversations:

i) What is frailty?

ii) What does it mean to me?

iii) How to support people who are deemed frail?

It was felt that there is a need to change the perception of frailty, especially in elderly people. It is important to know a person's baseline and for everybody to work together to improve health and quality of life at any age. There is a need to focus on prevention, conditioning, early intervention and slowing down the progression of conditions.

The group explored the concept of frailty beyond the elderly, highlighting the vulnerability of young people to online influences and mental health issues. There was concern about the physical frailty of the younger generation, noting that many children lack the strength to sit properly.

**Frailty is everyone’s business**

A person who is defined as frail is at high risk of adverse outcomes such as falls, immobility, delirium, incontinence, side effects of medication – and admission to hospital or the need for long-term care. People with frailty can be vulnerable to dramatic and sudden changes in their health due to, for example, infection, medication change or a new environment.

The group discussed the challenges faced by older individuals in navigating the healthcare system, particularly in accessing appointments and receiving adequate care. They also touched on the topic of acquired frailty, which can result from hospital stays and subsequent lack of appropriate care. The conversation ended with a focus on the need for more efficient healthcare services to address these issues.

The group discussed various aspects of healthcare improvement, focusing on preventative measures and community support. The importance of integrated care and joined-up thinking to address gaps in the system was highlighted and the need to recognize and support carers as essential partners in care. The conversations touched on fall prevention strategies, the role of volunteers in community services, and the potential for hospices to expand into preventative care.

There was a strong emphasis on prevention and living a personalised healthy life that provides good nutrition, sleep patterns and physical and mental exercise. One person cared for their spouse who had 16 co-morbidities.  
Picking up the pieces when someone you were caring for dies:  
<https://www.copescotland.com/resources/picking-up-pieces>

Managing healthcare appointments can be very confusing for the person and their carers. The appointments are often cancelled and rescheduled, they are often unclear regarding the condition or the purpose, they are not even clear as to who they are for – an issue when managing your own appointments and one or more dependents.

Polypharmacy, chronic pain, low mood, bereavement and other adverse events (past, present, future), loss of independence and interdependence (contribution), reduced continence, fear of going out, self-neglect, a life punctuated by healthcare appointments, and suicidal thoughts are often connected to frailty. A person living with multiple conditions, their carers or other close members have access to many means to take their own live.

The conversation touched on the importance of regular medication reviews, supported self-management within prescribed limits, and the need for personalized approaches to health management. There is an issue of over-prescribing and the lack of de-prescribing protocols. A personal experience was shared regarding sleep medications and the challenges of finding safe alternatives, emphasizing the need for caution when ordering medications online.

The group discussed the concept of anticholinergic burden and its potential impact on dementia progression and the importance of monitoring and reducing this burden including in mental health settings.

Anticholinergic Burden Calculator <https://www.acbcalc.com/>

1. **What is frailty?**

We challenged the common understanding that frailty is a natural part of aging. People live in health and wellbeing to over 100 years of age and so we approached frailty as, potentially, a temporary condition. Acute physical and/or emotional episodes can happen to anybody at any time and can result in one or more chronic conditions. There were concerns regarding healthcare bias connecting frailty with the elderly and a palliative and end of life care pathway.

1. **What does it mean to me?**

We agreed that we all wanted to maintain or improve our health, physically and emotionally, and that we needed access to the best evidence relevant to our own situations. This included mobility challenges, sensory impairment, previous conditions and interventions such as surgery and radiotherapy, mental health and other adverse events, carer responsibilities, cultural preferences and family backgrounds, financial resources, access to community including informal carers.

1. **How to support people who are deemed frail?**

It was agreed that prevention is better than cure, however, acute episodes and surprises happen with a need for responsive intervention: right service, right person. right place and right time. This is to prevent an acute incident becoming one or more long-term (chronic) conditions. It was felt that communicating to people with multiple long-term conditions (frailty) and their carers needed to be in-person and over an extended period such as an Admiral Nurse <https://www.dementiauk.org/information-and-support/how-we-can-support-you/what-is-an-admiral-nurse/> or a Carer Support Nurse <https://arc-eoe.nihr.ac.uk/research-implementation/research-themes/palliative-and-end-life-care/carer-support-nurse-pilot>

There were concerns that the frailty ‘pathway’ could remove hope, increase the feeling of being useless and a burden and reduce wellbeing resulting in social isolation, loneliness and even suicidal ideation.

Frailty must be approached holistically and sensitively: physically, emotionally and spiritually (culturally sensitive).

Where a person has become deconditioned support needs to be in place, including for carers, to not only support a person with reconditioning but encourage them to obtain an improved condition with the ability and motivation to maintain it.

Compassionate Communities is a must to meet the increasing demand of social isolation and loneliness and its impact on health and wellbeing. Zero Suicide alliance (ZSA) Social Isolation and Loneliness Training <https://zsa.frank-cdn.uk/scorm/social-isolation/story.html>  
Patient and Public Involvement for a person with chronic condition(s) and/or carers should be a hugely satisfying experience and an antidote to loneliness and loss of purpose.

The group were introduced to the Compassionate Neighbours programme, which facilitates companionship within communities, particularly for isolated or lonely individuals due to age or illness. <https://compassionateneighbours.org/>

A participant shared their experiences with a community organization called Contact the Elderly, which has since rebranded as Re-engage UK.

<https://reengage.org.uk/volunteer/new-volunteers/become-call-companion/?kw=contact-the-elderly-exact&utm_source=google&utm_medium=cpc&utm_campaign=novi---re-engage---call-companion---exact&utm_term=contact-the-elderly&gad_source=1&gclid=CjwKCAjwwLO_BhB2EiwAx2e-36UL8fnPq6YOQcI8mRmBENZAckDd13c58nw9Xe-bAAuPLzOuVo3KmhoCa3IQAvD_BwE>

**Carers in Hertfordshire**  
Keeping in Touch Volunteers

<https://kamino.fra1.cdn.digitaloceanspaces.com/cih/app/uploads/2024/07/KIT-Volunteer-Role-Description-June-2024.pdf>  
Mentoring Volunteers  
<https://kamino.fra1.cdn.digitaloceanspaces.com/cih/app/uploads/2022/12/Volunteer-Mentor-Role-Description.pdf>

Ageing well and frailty Public Communications Toolkit  
<https://www.hertsandwestessex.ics.nhs.uk/your-health-and-care/stay-well/ageing-well/frailty-communications-toolkit/>

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