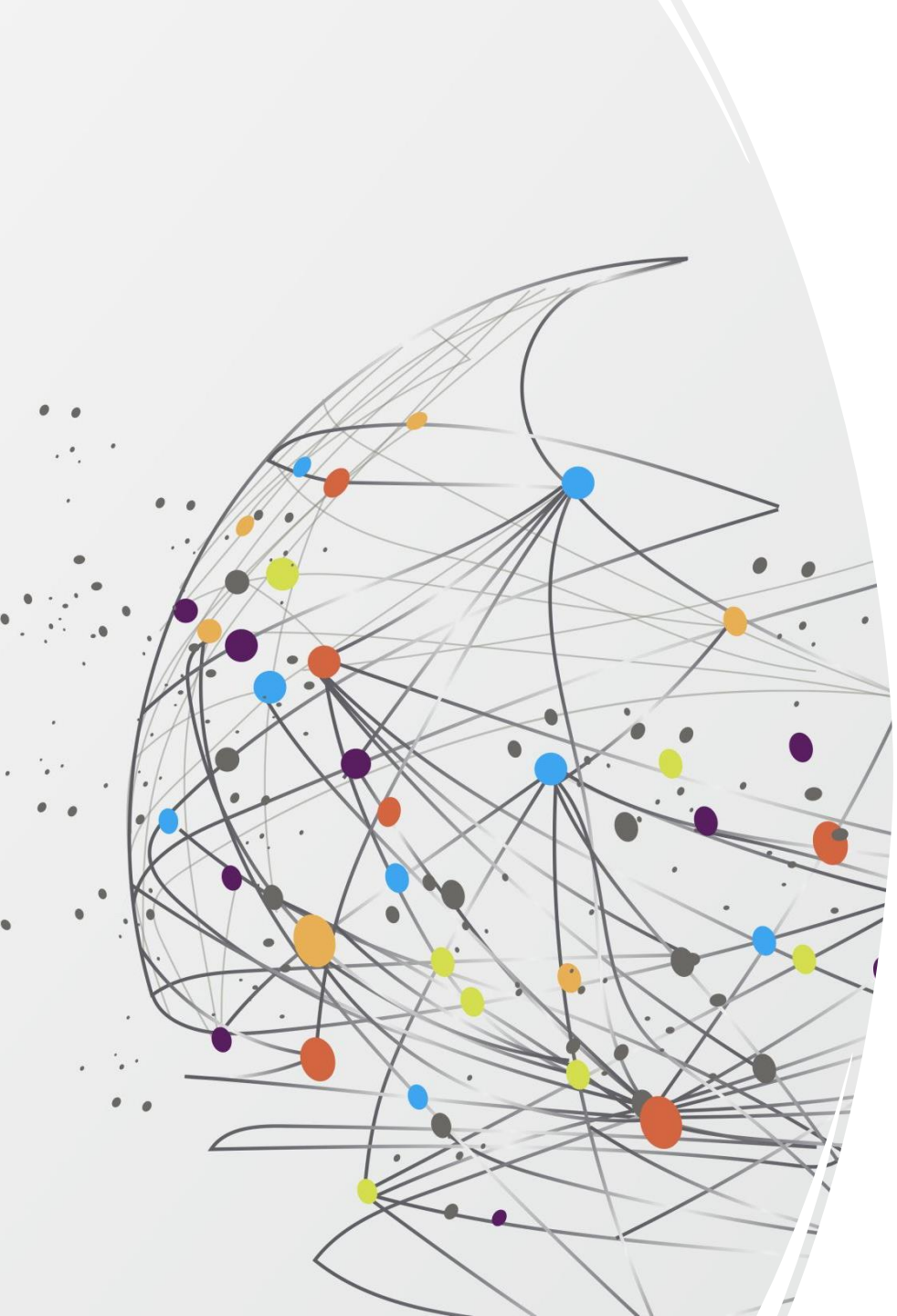


Welcome to Workshop 3: **End of life care for people experiencing dementia**

- Jonathan Hanbury, The Ness Care Group
- Len Jarman, CHES team, Torbay
- Dr Gill Horne, Rowcroft Hospice

Brief outline for this session

Who we are?
Context : Why this session is important?
Identifying deteriorating health in dementia
Challenges in care with deterioration/end of life
Brief introduction to legal issues
The future & innovations in dementia care
Resources for people with dementia, their carers and health & social care professionals
Q & A

Biographies

Lennon

As a Social Worker in Chess I am responsible for assisting clients with challenging behaviour from a non-pharmacological perspective.

I am also responsible for conducting relevant assessments, e.g. an MCA related to care and welfare.

I advise on appropriate Care Home placements and designing bespoke 1 to 1 Care Plans.

Our team consists of Mental Health nurses, a Social Worker (me) and a Community Care Practitioner.

The Mental Health nurses in our Team are primarily responsible for reviewing medication and making changes where necessary.

Our focus is on education within Care Homes and intervening with clients displaying challenging BPSD as a result of Dementia. All our clients reside in Care Homes and have a Dementia diagnosis.

I am also a motivational speaker

Jonathan

I am the Founder and CEO of The Ness Care Group. The Ness was set up to look at ways to innovate and change the way we work with families and individuals living with dementia in the community.

I build Community Memory Hubs that look to actively treat the illness, to teach health & social care teams and offer respite to carers. Six years on we have 4 sites across Devon and run outreach CST sessions across most of Mid/East & South Devon.

I am passionate about changing the way we look and work with dementia in the community.

Prior to launching The Ness, I spent 20 years working in the NHS. I started my clinical career as a nurse specialising in palliative care, cancer and neurodegenerative disease, before moving into senior NHS management and finishing in the NHS as Director of Nursing helping to lead some of the largest hospitals in central London.

My interests today are in building social enterprises that explore technology to help solve the social care crisis... that is when not looking after my 4 and 6yr olds!

Gill

I currently work as Programme Director - Care Services at Rowcroft Hospice in South Devon, having previously been Director of Patient care there for 12 years. I'm a registered nurse with 40 years of experience as a nurse and clinical leader in the UK and Canada, having worked in specialist palliative care/hospice services for the last 23 years. I completed a PhD in 2011, which sought the perspectives of people affected by lung cancer about the expression of wishes for end-of-life care. I have published papers on ACP, palliative care for heart failure and other palliative care topics

My role is to clinically and operationally lead the development of a new purpose built 60-bedded nursing home for people with advanced dementia and complex nursing needs and the redesign of the hospice.

In my spare time I enjoy my role as a PRiME volunteer tutor, supporting the design and facilitation of palliative care training in Cambodia, Indonesia, Pakistan and Uganda. I'm married with an adult son, enjoy walking in the countryside with our dog and sea-swimming.

Context

It is estimated **one in three** people born in the UK today will develop dementia in their lifetime.

It is estimated that between **11,000** - **14,000** people are living with dementia in **Devon**.

Alzheimer's Society state dementia costs the UK £**34.7bn** a year, a figure that will rise to £**94.1bn** by 2040.

By this same year, 1.6m people are expected to be living with dementia in the UK.

Over **700,000** carers of people with dementia in the UK

Carers of people with dementia experience particular difficulties due to the complex, unpredictable and progressive nature of the disease

Identifying deteriorating health in dementia 1

Important to understand the different types of dementia and the different ways these will impact an individual's health:

- Alzheimer's Disease
  - Familial Alzheimer's (Early On-Set)
  - Advanced Age Alzheimer's
- Vascular Dementia (Mixed Dementia)
- Frontal Temporal Dementia
- Lewy Bodies Dementia

Identifying deteriorating health in dementia 2

Recognising alternative ways of communicating in end stage dementia.

- Non-Verbal Communication
- Validation Therapy
- Challenges to good communication and some potential solutions

Identifying deteriorating health in dementia 3

Symptoms and potential health risks in late stages of dementia

(in many respects like other end stages chronic illnesses)

- Managing Skin– Pressure damage
- Managing someone with dementia who is bed-bound
- Recognising and treating the co-morbidities associated with frailty – chest Infections, cardiac disease, lung problems and arthritic pain.
- Symptoms that can challenge at end of life – Psychosis, acute delirium, confusion, hallucinations
- Supporting someone at end-of-life with anorexia and dysphagia

Challenges in care with deterioration

- Recognising when dementia has tipped from severe dementia into end of life
- Lack of education, skills of care home and domiciliary care workers
- Medication and end of life – the risks in using traditional medication?
  - Are there any?
- ACP – it's never too soon to start!
- Quicker deterioration in institutional care settings
- Burn-out for families/carers and need for education for families/carers
- No decision about me without me!
- Predicting and managing 'challenging' behaviour
- Focus is on physical and personal care in lieu of meaningful occupation & QOL
- Assessing and managing pain/distress
- Prognostication and access to end-of-life care services
  - Perception by public/HCPs - hospice services only for patients with cancer!

End of life care indicators in dementia - BGS

- Reduction in verbal communication, inability to answer questions or obey commands.
- Inability to recognise family and close friends.
- Inability to walk or do any other purposeful activity.
- Loss of weight/decline in appetite and thirst/decline in oral intake/loss of weight.
- Incontinence of urine and faeces.
- Recurrent infections.
    - End of Life Care in Frailty: Dementia | British Geriatrics Society (bgs.org.uk)

Also check out: How to know when a person with dementia is nearing the end of their life | Alzheimer's Society (alzheimers.org.uk)

Brief overview of key legal issues

The Mental Capacity Act 2005 is designed to protect and empower individuals who may lack the capacity make their own decisions about their care and treatment

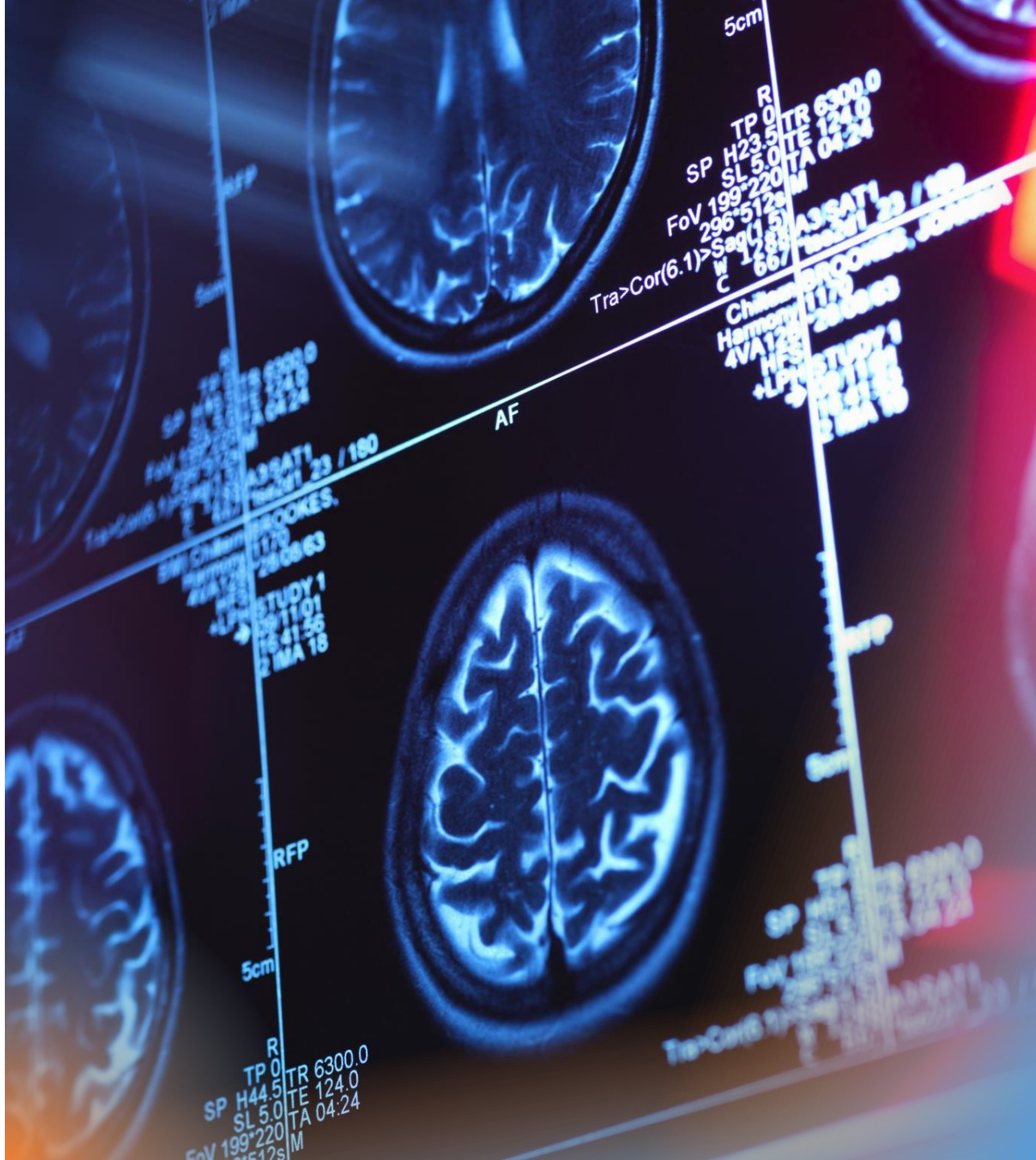
The MCA:

- assumes a person has the capacity to make a decision themselves, unless it's proved otherwise wherever possible,
- help people to make their own decisions
- do not treat a person as lacking the capacity to make a decision just because they make an unwise decision
- if you make a decision for someone who does not have capacity, it must be in their **best interests**
- treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedom

Deprivation of Liberty Safeguards are part of the Mental Capacity Act

- They are a set of checks to protect individuals in Care who have had their liberties restricted EG a locked door in a Care Home
- This legislation *only* applies to individuals in Care Homes and hospitals
- A deprivation of liberty is when a person has their freedom limited in some way.
- It occurs when: '**The person is under continuous supervision and control and is not free to leave, and the person lacks capacity to consent to these arrangements**.'
- A deprivation of liberty is common for a person with dementia receiving care who may have:
  - decisions made for them or on their behalf
  - limitations on where they are allowed to go
  - their routine decided for them.
- Eventually, most people with dementia will need a high level of support. Sometimes the person's freedom is limited to give them the care they need, or to prevent them from harm. For example, a care home or staff in a hospital may stop the person from walking around at night or leaving the building or give them medications that may affect their behaviour.
- In protecting an individual's deprivation of liberty, you are trying to make sure that any care that limits a person's liberty is done in the least restrictive way and is in the person's best interests.

The future and innovations in dementia care



The future and innovations in dementia care

- The current system does not work for Health and Social Care Teams, families and those living with dementia.
- In too many cases individuals with moderate to advanced dementia are in inappropriate care/nursing homes. Staff are not trained, and environments not designed to manage this complex illness.
- We need to stop seeing this illness through the social care lens and just like in the treatment of cancer and cardiac disease treat it as the biological illness.
- In the future we need to focus on 3 things!

The future and innovations in dementia care: 1

How to better help maintain individuals in their own homes until the final stages.

- Using technology to help support the individual
- Working closely with the families to understand the disease
- Offer specialist non-pharmacological treatment designed to delay deterioration
- Create a better system of respite that allows a carer regular time out.

The future and innovations in dementia care: 2

Switch our health funding away from acute services and towards preventative and community solutions.

- Current funding focus's on acute breakdown and reactive involvement by social care, GP or A&E this needs to change
- Focus on using technology to prevent acute admissions,
- To help the individual stay active, social, healthy in their community by funding specialist community care
- Fund more respite beds and respite services

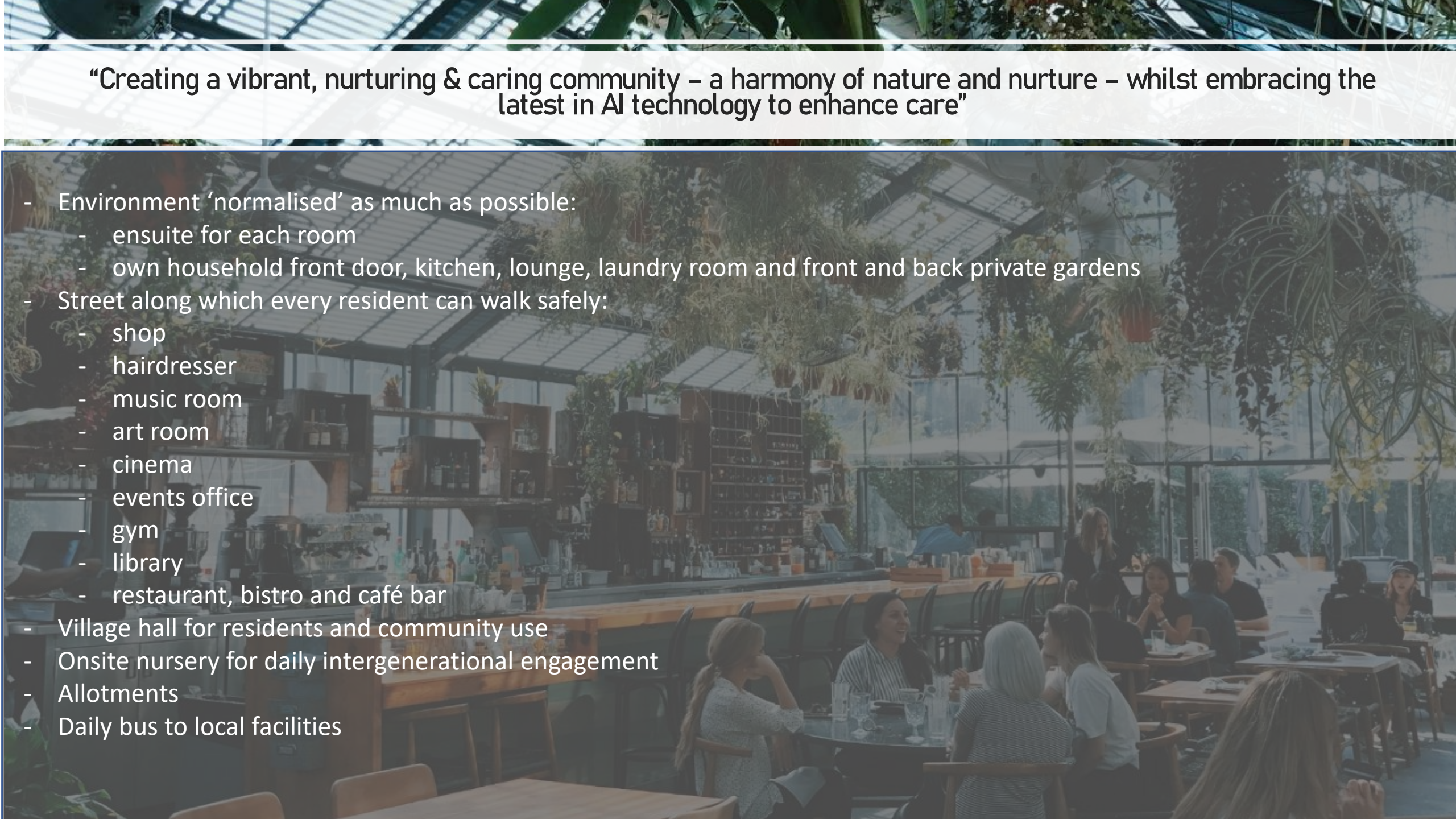
The future and innovations in dementia care: 3

Build purpose-built specialist dementia care homes that become centres of excellence and support a larger area (allowing current generic care homes to help those with mild or no diagnosed dementia).

- Look to cancer & cardiac centres of excellence as evidence
- Recognise that those living with dementia need very different, expert care at end of life
- Recognise that staff need to understand the disease and the best way of helping someone living with dementia.
- The architecture should be designed with dementia in mind. Too often those living with dementia are placed in old Victorian houses that reduce mobility and activities of daily living.
- Utilise the latest technology.

LOOK TO THE EXAMPLE BELOW!

Best in class complex nursing & specialist dementia nursing home in 23 acres of Ella's Gardens, Torquay, Devon

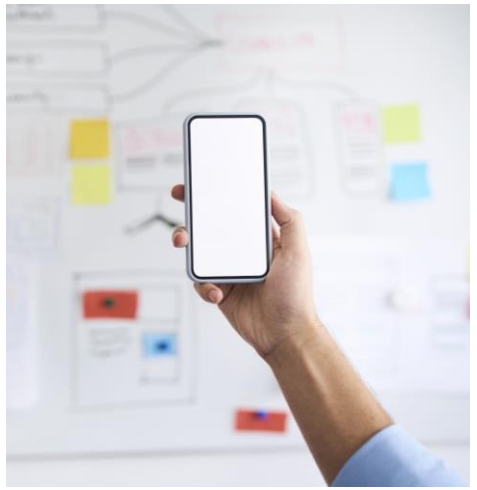


"Creating a vibrant, nurturing & caring community – a harmony of nature and nurture – whilst embracing the latest in AI technology to enhance care"

- Environment 'normalised' as much as possible:
  - ensuite for each room
  - own household front door, kitchen, lounge, laundry room and front and back private gardens
- Street along which every resident can walk safely:
  - shop
  - hairdresser
  - music room
  - art room
  - cinema
  - events office
  - gym
  - library
  - restaurant, bistro and café bar
- Village hall for residents and community use
- Onsite nursery for daily intergenerational engagement
- Allotments
- Daily bus to local facilities

Digital and AI innovations

- Electronic care records are expected to be in all care homes, with most accessing ‘GP connect’ (no ‘*outstanding*’ CQC rating without)
- TOPOL digital fellowship – digital/AI decision-making framework for use by care homes, codesigned with people with experience of dementia
- ‘Tech for Better Care’: co-design of an App/wearable for people at end of life and their families to connect to Rowcroft hospice from a person’s home
- Two other AI concepts being funding by an AWS IMAGINE Grant 2023-2024 aims to support freedom, choice and control for people living with advanced dementia in care homes



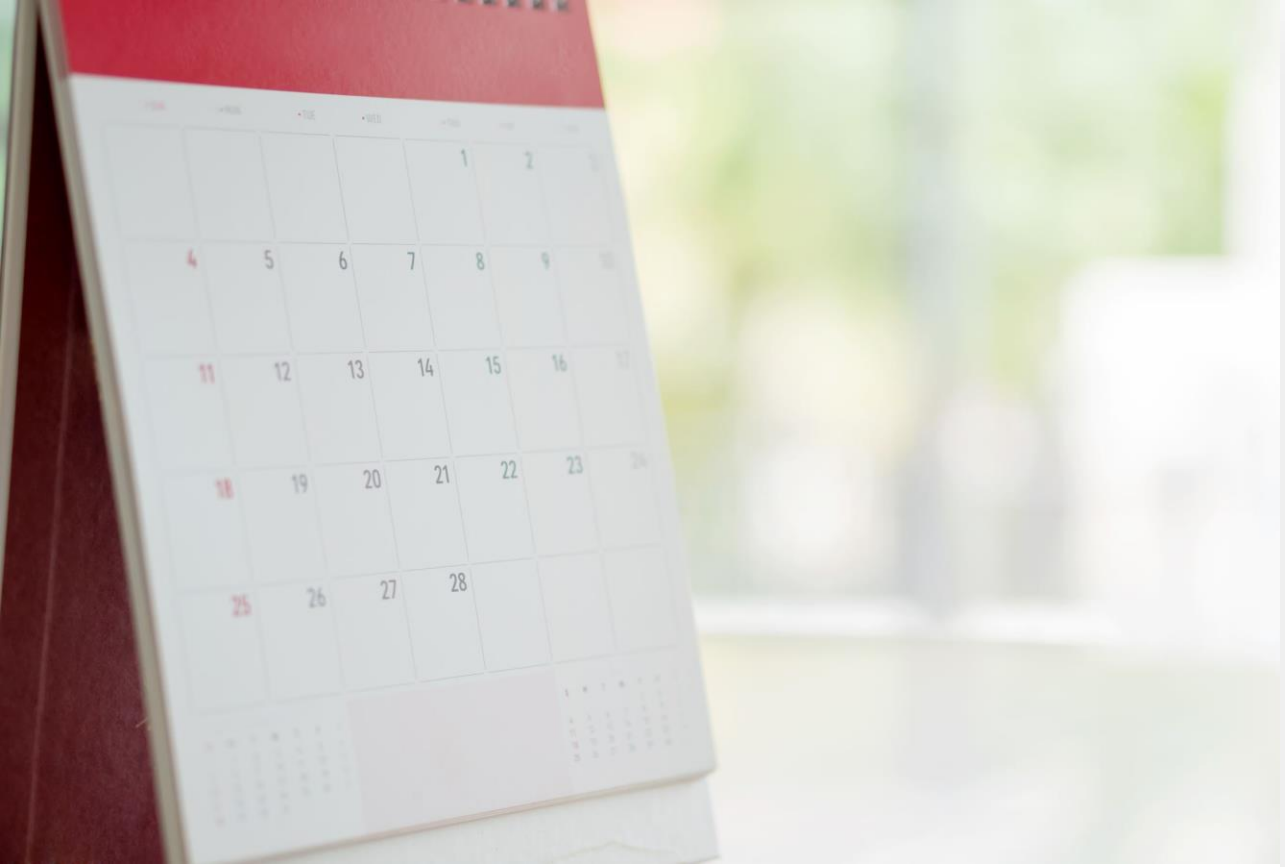
Support/resources

For people experiencing dementia

- Dementia UK: Information and support - Dementia UK
- Age UK: Dementia support services in your area | Age UK
- Alzheimer's society: Memory aids and tools | Alzheimer's Society (alzheimers.org.uk)
- The Ness Care Group: Ness Care | Dementia Care | Dementia Respite & Therapy (nesscaregroup.co.uk)
- FILO project: The Filo Project | Award winning dementia day care
- Living with dementia: Living with Dementia Toolkit

For health and social care staff

- ACP tool: my-future-wishes-advance-care-planning-for-people-with-dementia.pdf (england.nhs.uk)
- DIADEM tool for diagnosing advanced dementia in care homes:
  - https://diadem.apperta.org/
- PINCHME tool: End of Life Care in Frailty: Delirium | British Geriatrics Society (bgs.org.uk)



Dementia and palliative care conference

- **March 26th**

International and national expert speakers

Save the date…

Thank you for listening

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