

■ Neglected populations

Improving practice and policy

Professor Meera Agar

IMPACCT – Improving Palliative, Aged and Chronic
Care through Clinical Research and Translation



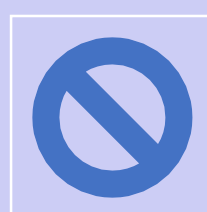
Acknowledgement
of country



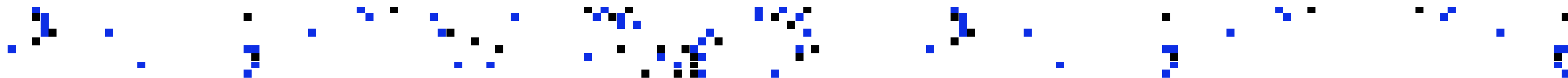
Dictionary definition of 'Neglected'



Suffering a lack of proper care



Not receiving proper attention, disregarded





Population

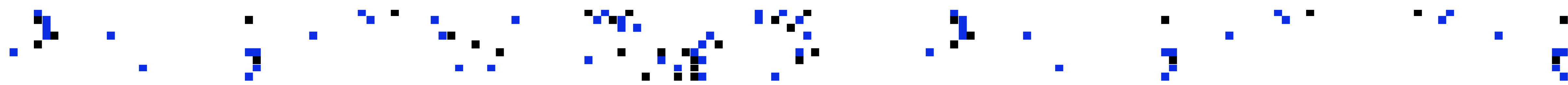


Health services



Individuals

POLICY, LAW, FUNDING, ATTITUDES, KNOWLEDGE/SKILLS



One of six guideline principles – National palliative care strategy

Care is accessible

All Australians will be able to access quality palliative care. There are population groups that are currently under-served, including people who are:

- Aboriginal and Torres Strait Islander
- culturally and linguistically diverse, particularly new migrants
- lesbian, gay, bisexual, transgender and intersex
- living with disability, including cognitive impairment such as dementia
- experiencing homelessness
- in long-term institutional care (including being incarcerated)
- ageing and frail
- living in rural and remote areas.

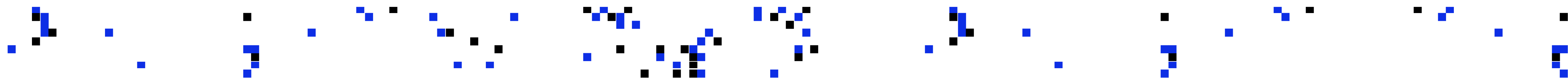
While many people across society will experience varying levels of access and quality of care, these population groups generally experience additional barriers in accessing services, which will be addressed in initiatives to improve access and equity of care.

Palliative care needs to be flexible and responsive to ensure that care is accessible respectful, culturally safe and appropriate according to need. Specialist palliative care services play an important role in meeting complex needs and supporting others to provide this care.

<https://www.health.gov.au/sites/default/files/the-national-palliative-care-strategy-2018-national-palliative-care-strategy-2018.pdf>

What are the types of under-service which can occur

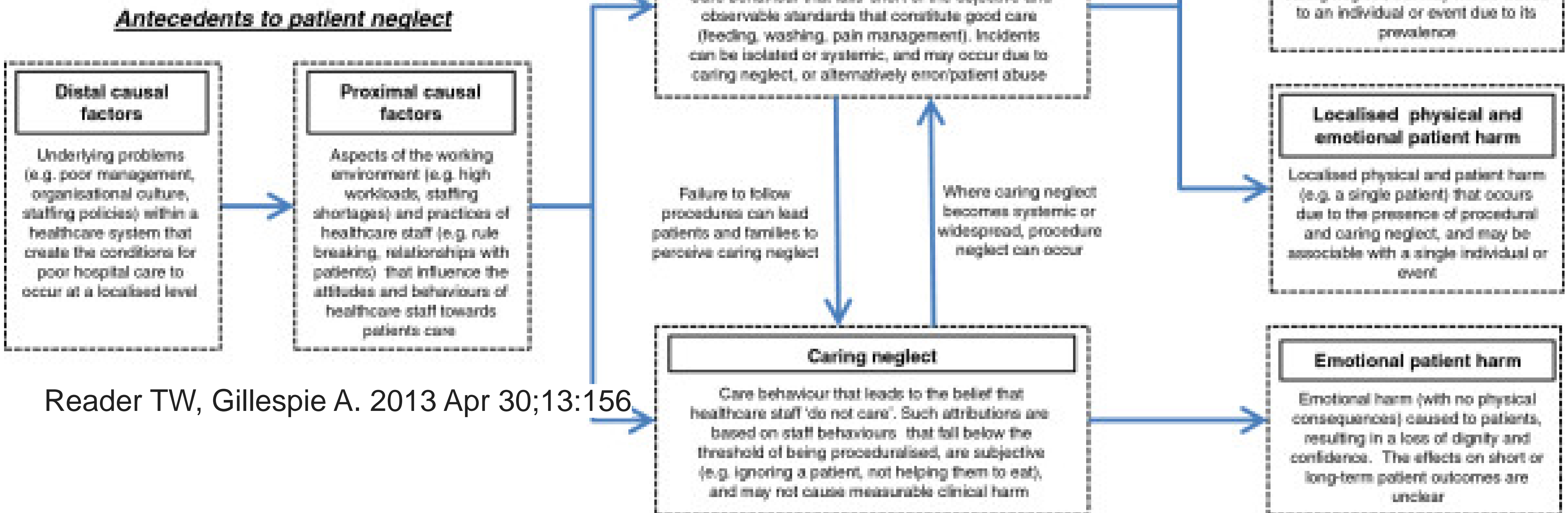
- **No access**
 - Service doesn't exist
 - Mechanisms to reach service (practical, information, individual/community barriers)
 - Funding/resources limit volume of clients or type of clients
- **Access but to 'not fit for purpose' and/or 'unsafe' services**
 - Top down approach to service development
 - One size fits all models
 - Not trauma informed
 - Not culturally responsive



What are the types of under-service which can occur

- **Late access**
- **Poor quality care**
 - Not underpinned by evidence
 - Staff not adequately trained or limited scope of practice
 - Impacted by systemic biases/discrimination (ageism, racism, stigma)
- **Unidimensional care**
 - often with a biomedical focus
 - Not collaborating with community/social care
 - No role of related non-health services (correctional services, disability support)
 - not underpinned by culturally or trauma informed care

Do we also need to be considering lack of access to palliative care in a broader conversation about errors in health care, patient abuse and harm?



Reader TW, Gillespie A. 2013 Apr 30;13:156



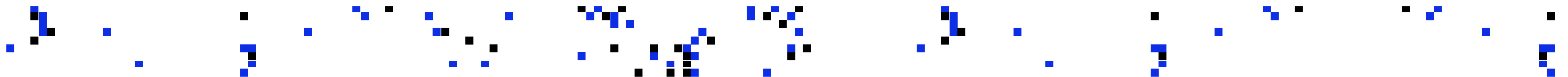
UNSW
Department of
Developmental
Disability
Neuropsychiatry

**Tailored model of care for people
with intellectual disability**

Background

- A survey of NSW health professionals found 63% of respondents did not believe that their service was equipped to meet the needs of people with intellectual disability
- People with intellectual disability are more likely to experience life-limiting conditions as they age with leading causes, respiratory, cardiovascular, cancer and neurological conditions
- Multiple barriers to quality palliative care
 - Delayed diagnosis, inequity in access to supported accommodation, late access or no access to specialist palliative care

https://www.3dn.unsw.edu.au/sites/default/files/documents/National_Toolkit_health_professionals.pdf



What do you think helps people with intellectual disability to have a good end of life?

***“Ah, to be happy.
And be – and be –
- comfortable.”***

Person with intellectual disability¹

Guiding principles of the model

Diagram 1: Guiding principles underpinning the Tailored model of palliative care for people with intellectual disability³.



Human rights are protected, respected and upheld as per the United Nations Convention on the Rights of Persons with Disabilities



Family, carers and supporters are recognised and valued as partners in providing palliative care, when desired by the person with intellectual disability, and are supported to enact their roles



Palliative care is person-centred and holistic



Access to quality care is equitable



Dying, death and grief are recognised as part of life



Care is well-coordinated and integrated



Care is high quality and evidence-based

For guidance on how to implement the guiding principles, see **Part 3**.

³ The Guiding principles were determined through an international Delphi study as part of 3DN's research project Improving palliative care services for people with intellectual disability. Find out more about this study on the [project website here](#).

Timely diagnosis of life limiting conditions

<https://www.health.gov.au/sites/default/files/2023-05/adult-comprehensive-health-assessment-program-chap-annual-health-assessment-for-people-with-intellectual-disability.pdf>

Part 1 – For the Person with Disability

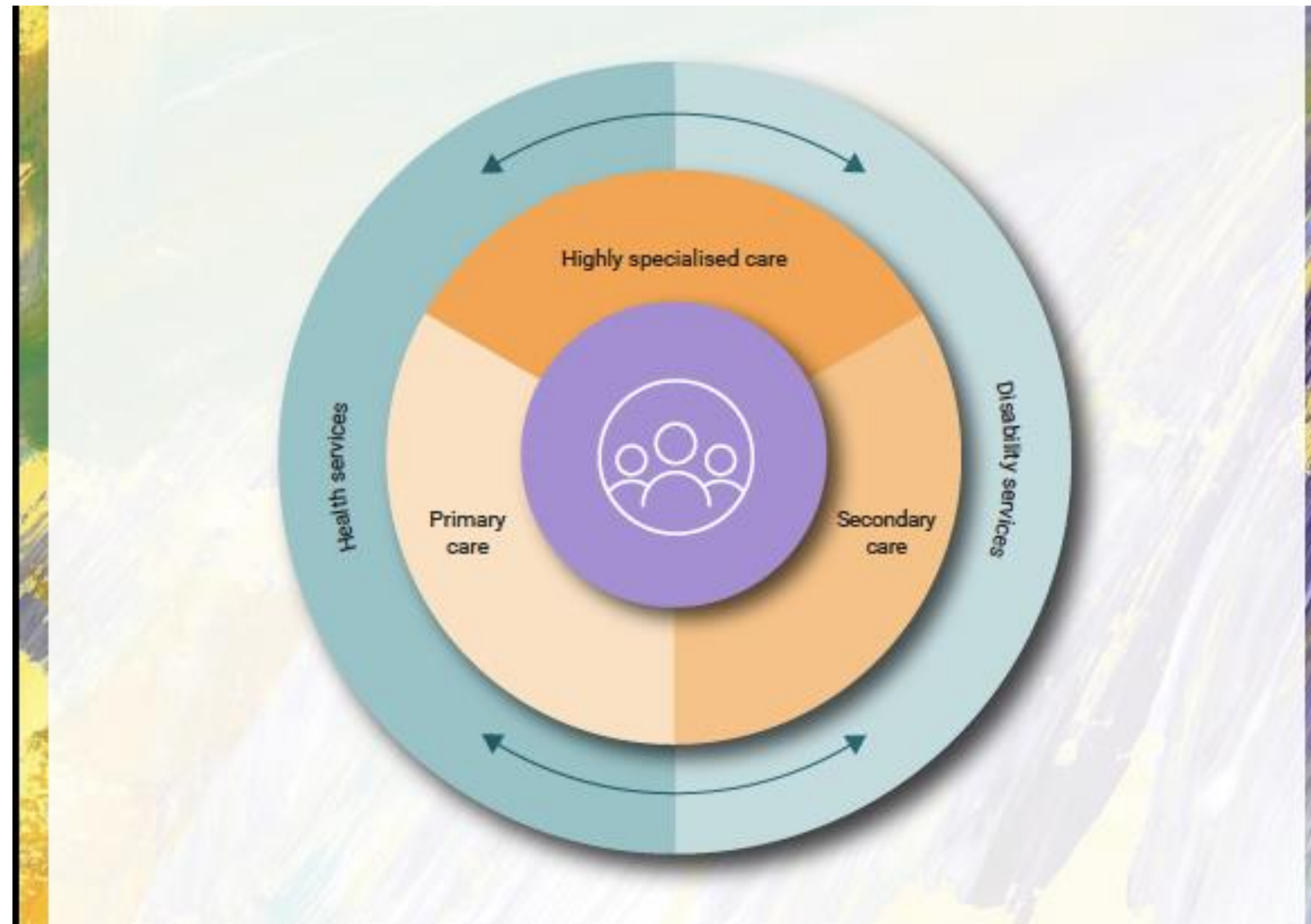
Please tick the boxes below if the person has experienced any of the following signs and symptoms in the **last year**.

If you are unsure or don't know the answer, please tick the 'unsure/don't know' box.

To make an accurate medical assessment of the person's health, the doctor needs to know about these signs and symptoms.

	Yes	No	Unsure/ don't know
1. Breathing system			
Does the person cough?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person cough up blood ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person cough up stuff/mucous/sputum ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person get short of breath ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person wheeze ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Heart system			
Does the person have chest pain ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person's heart ' race '/beat quickly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do the person's ankles swell ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person get short of breath while lying in bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person get a blue tinge to their skin (for example, fingers/lips/toes)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Muscles & Joints			
Does the person have joint pain or back pain ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person have muscle pain ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Gastrointestinal system			
Has the person lost weight ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person have trouble swallowing ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person regurgitate/vomit ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person get heartburn ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person have diarrhoea ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person have black bowel motions/faeces ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person get constipated ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person lose control of bowel movements ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person have abdominal/stomach pain ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Urinary system			
Does the person have pain when urinating ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person have blood in the urine ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person urinate involuntarily/suffer incontinence ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does the person urinate a lot/more than usual ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Model components



Clinical strategies

"Prepare [them] for what's going to happen...make sure they know all about what's going to happen in the end."

Person with intellectual disability

"...the issue around coroner's cases is often a barrier, I think staff in group homes are often scared...if the person dies in the group home...it becomes a coroner case and I think there is a stress and anxiety around that."

Health professional

Organisational strategies

"I think what would be useful for the palliative service is having access to education about how best to communicate with people [with] intellectual disability.."

Health professional



About palliative care



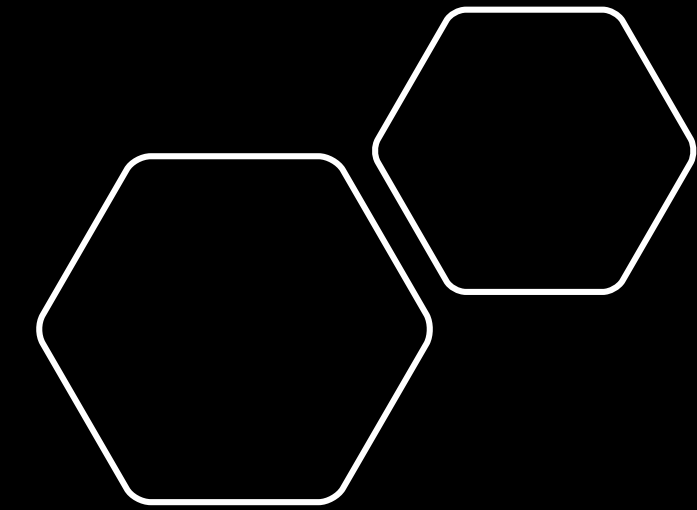
Palliative care is help for people who have a serious health condition that they will die from.

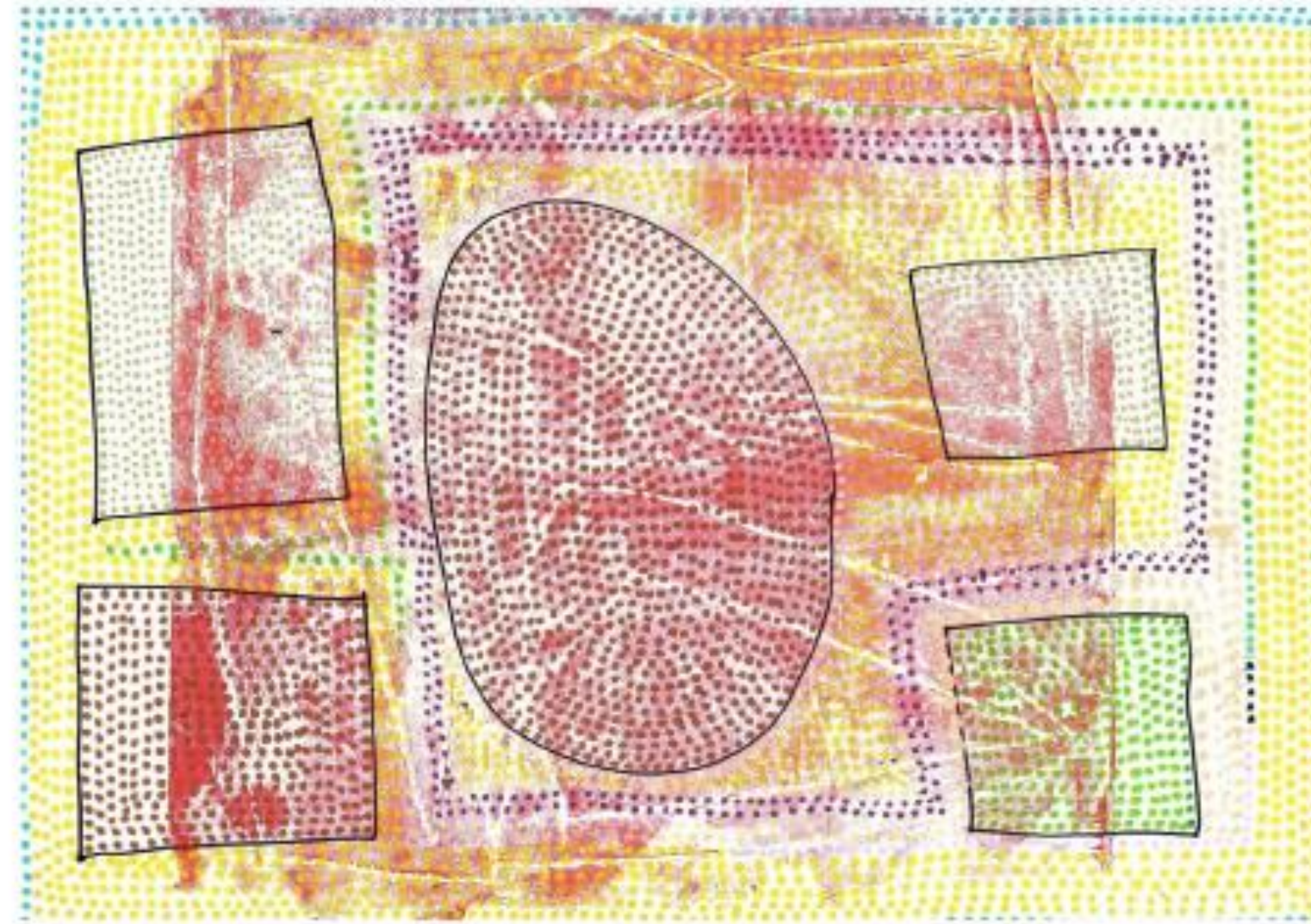


When a person dies it means that their body has stopped working and their life has ended.



Palliative care helps people manage their **symptoms** so they feel well until they die.





Bridget Kelly
Printing Shapes, 2024

A story about Joe getting good palliative care

The story



During the appointment



The **palliative care team** use simple words and **Easy Read** to communicate with Joe.



The **palliative care team** ask Joe



- What do you like?
- What don't you like?
- What is important to you?

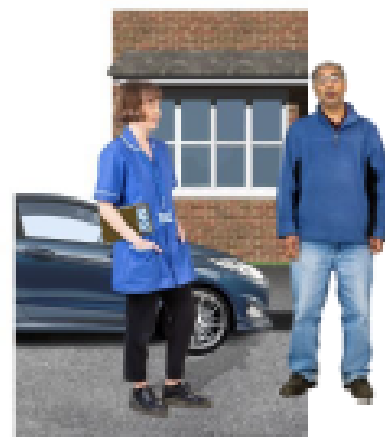
After the palliative care appointment



Everyone follows the plan to support Joe.

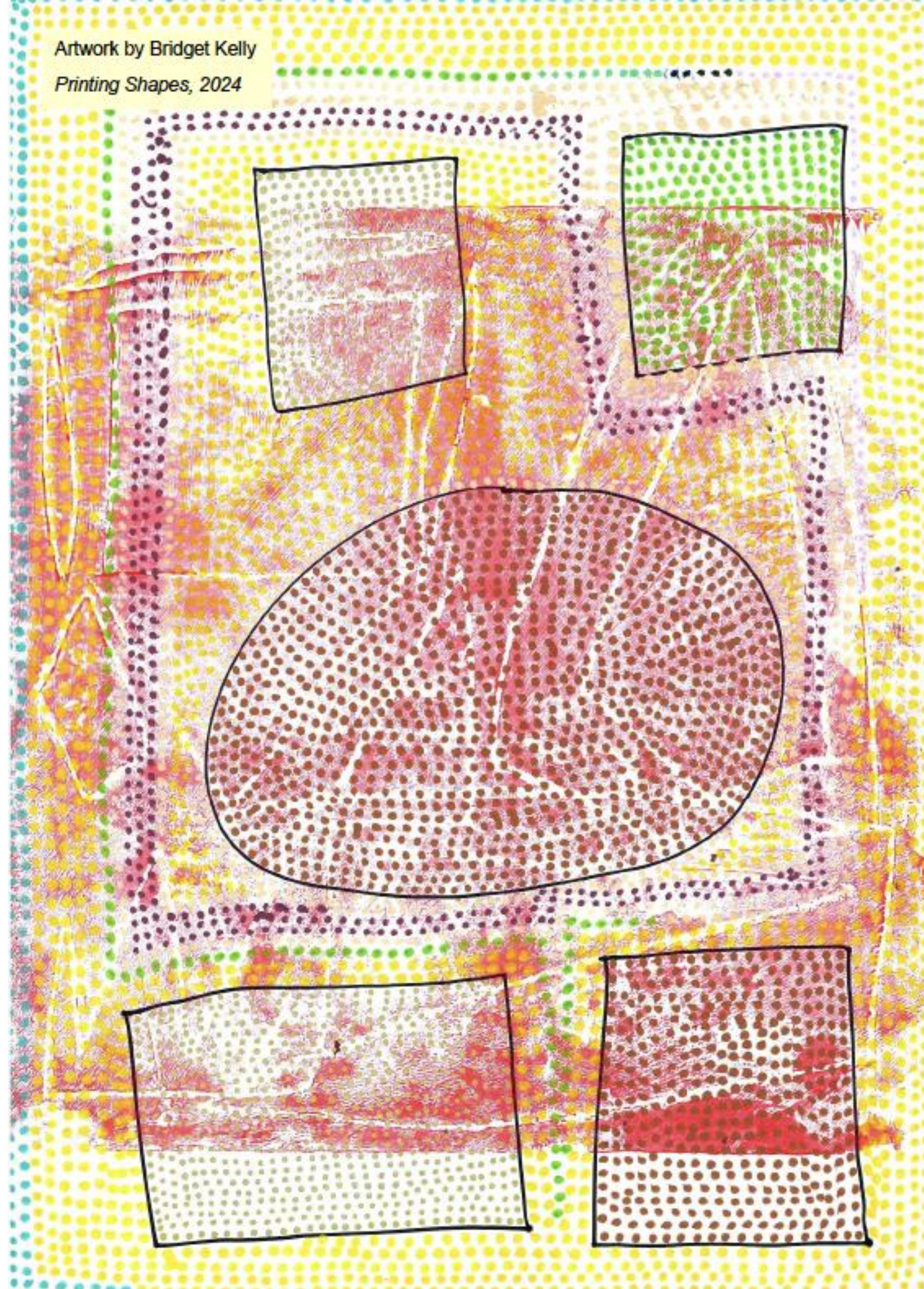


Joe is given **medicine** to help with his pain and sickness.
Medicine is sometimes called medication or drugs.



The **palliative care team** visit Joe in his house every week.

Artwork by Bridget Kelly
Printing Shapes, 2024



Artist: Bridget Kelly

www.studioartes.org.au