

# Mapping patient and carer experiences with injectable anticipatory medications for timely symptom control in community settings.

**Dr Rosanna Fennessy**

**Artemis Paterson, Dr James ward. Prof J Clarkson, Dr Ben Bowers**

**Palliative and End of Life Research Group in Cambridge (PELiCam) - Primary Care Unit**

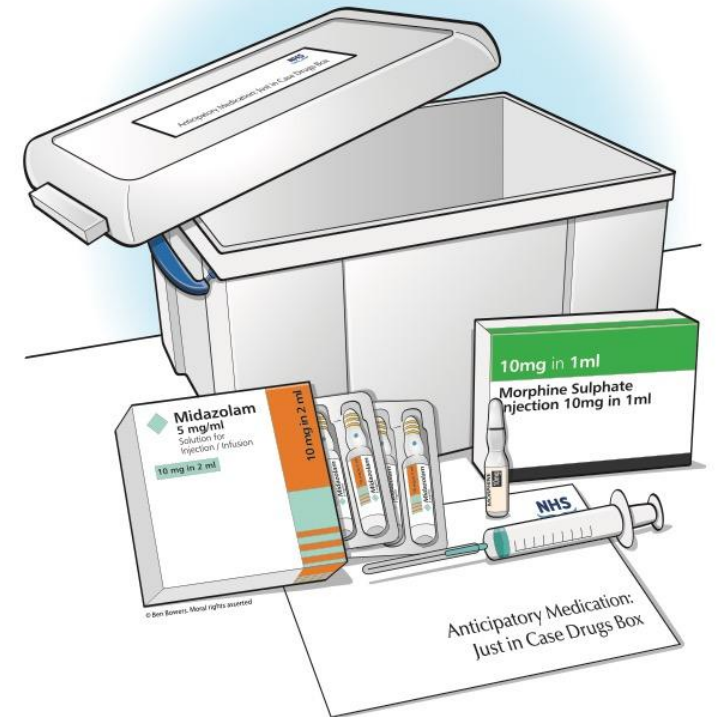
# Sharing and re-use of patient journey illustrations

Our patient journey presentation and its illustrations are part of an ongoing project at the Palliative and End of Life Care (PELiCam) research group in Cambridge.

- Please do not reuse these slides without permission from the research team – Dr Rosanna Fennessy, Artemis Paterson and Dr Ben Bowers.
- If you would like to contact us about using the content, please email Dr Rosanna Fennessy at [rtf21@cam.ac.uk](mailto:rtf21@cam.ac.uk)

# Background

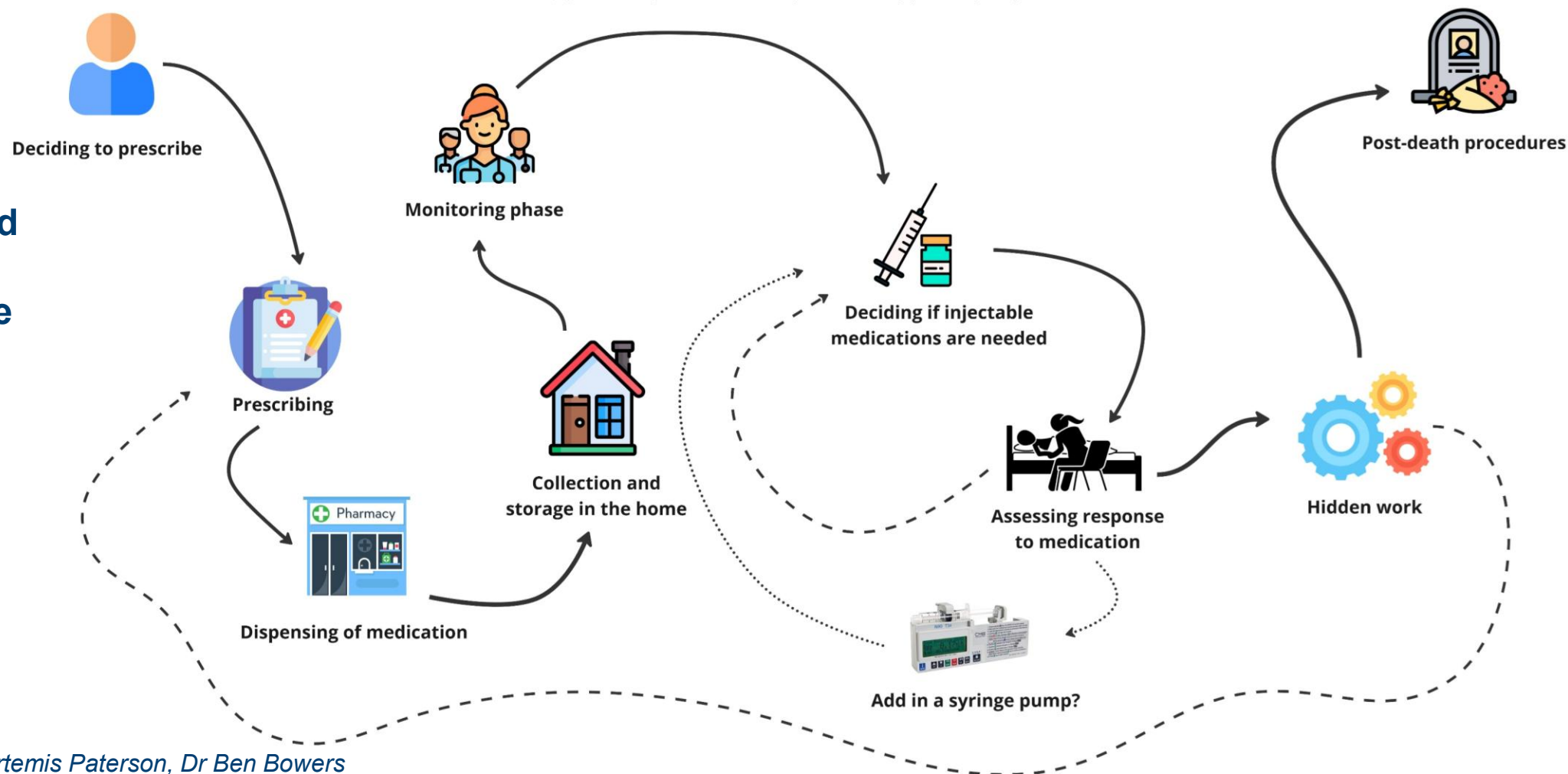
- Injectable anticipatory medications are routinely prescribed ahead of need for distressing end-of-life symptoms in community settings
- Typically prescribed by GPs, stored at home and administered by visiting district nurses or paramedics



*Dr Rosanna Fennessy, Artemis Paterson, Dr Ben Bowers*

# Background: Intended injectable anticipatory medication pathway

Systems around anticipatory medications are complex involving decisions and activities for healthcare professionals, patients and carers



Dr Rosanna Fennessy, Artemis Paterson, Dr Ben Bowers

# Aim: To understand patient journeys navigating injectable AM care

**Journey mapping approaches** from engineering and inclusive design typically used to improve patient safety. However, less used to illustrate and understand patient/carer narratives of their experience of navigating healthcare systems.

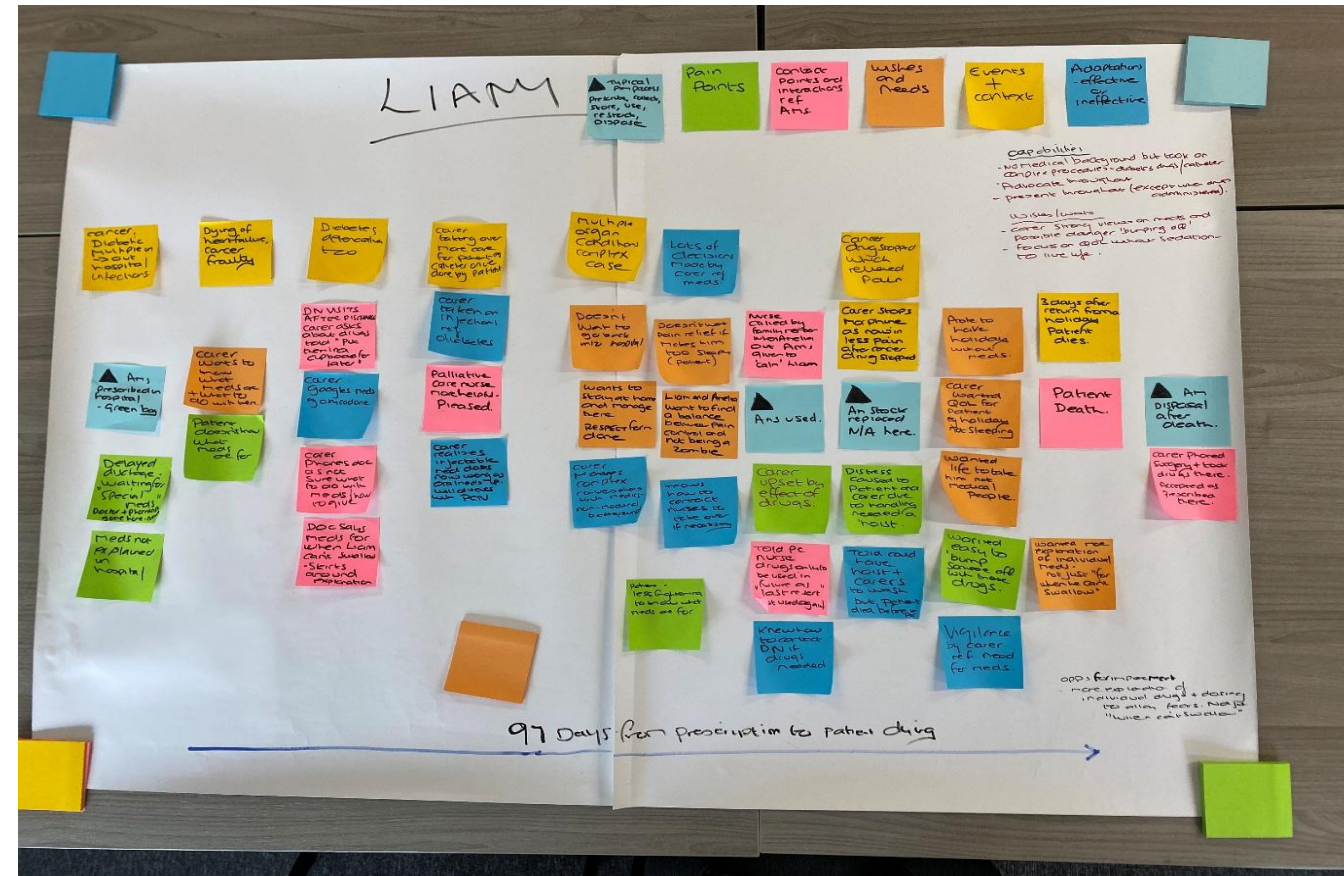
## **Secondary analysis of longitudinal multi-perspective interview data**

- 11 patient centred cases including informal carers and healthcare professionals
- 6 patients, 9 carers, 6 healthcare professionals took part (total 28 interviews)



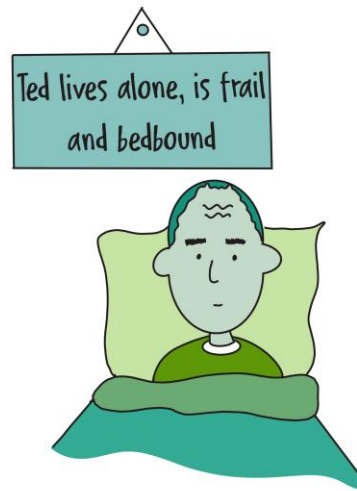
## Data analysis – stage 2 – personas and mapping journeys

- Journeys mapped visually alongside intended journey
- Three recurring “pain points” which influenced these journeys and were reflected in all 11 cases
- Journeys and implications for practice discussed with PPI group



# Three recurring findings – “pain points”

- Perceptions of anticipatory medications – what they are and what they are not
- Quality of information exchange between patients/carers/healthcare professionals – threshold for medication use, channels of communication to discuss AMs
- Ability to navigate healthcare systems - according to individual context and over time



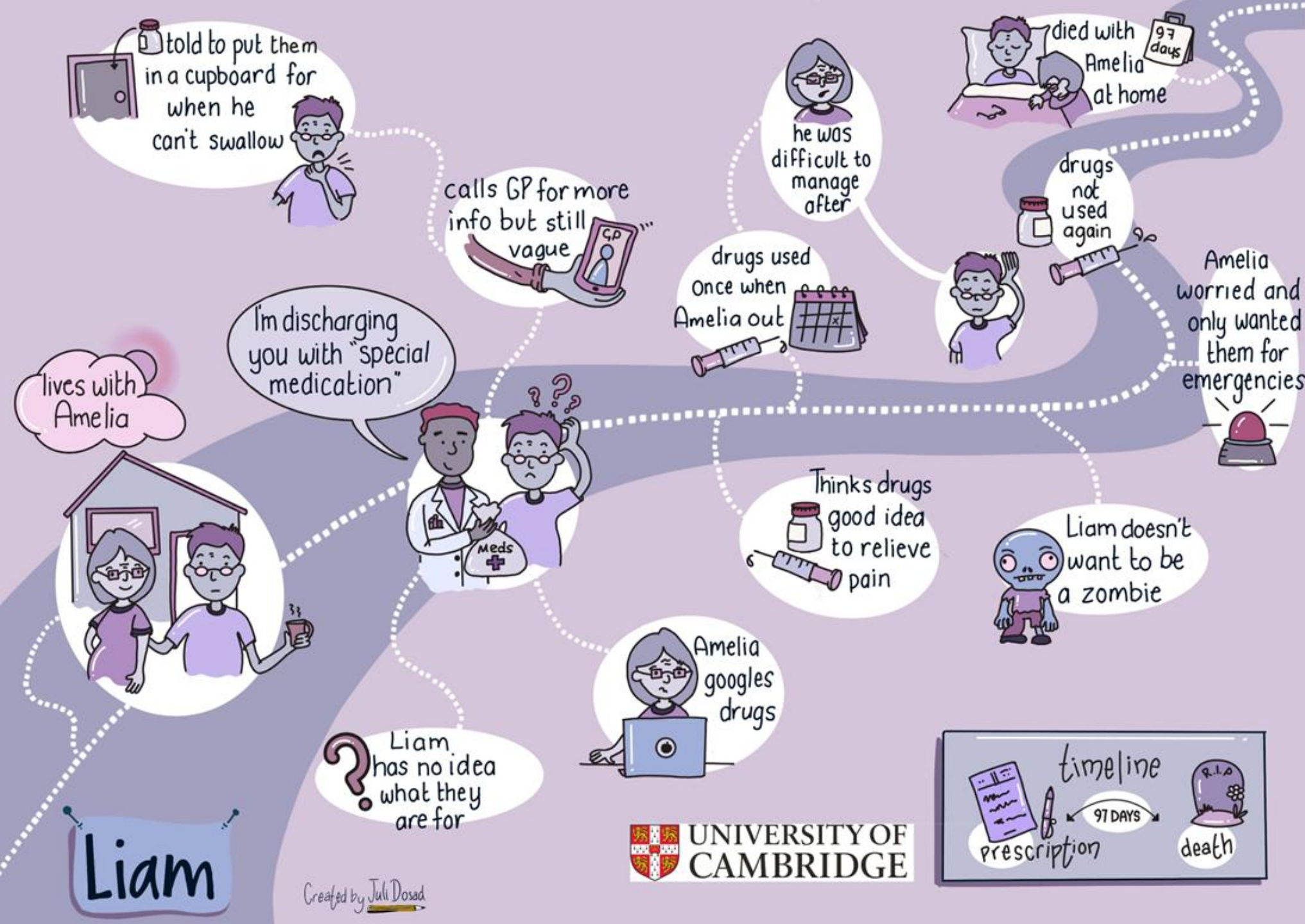
*Dr Rosanna Fennessy, Artemis Paterson, Dr Ben Bowers*



# Perceptions of anticipatory medications

Liam:

- 73 years old
- Cancer and heart failure
- Gradual deterioration
- AMs prescribed 97 days before death



Dr Rosanna Fennessy,  
Artemis Paterson, Dr  
Ben Bowers  
(rtf21@cam.ac.uk)

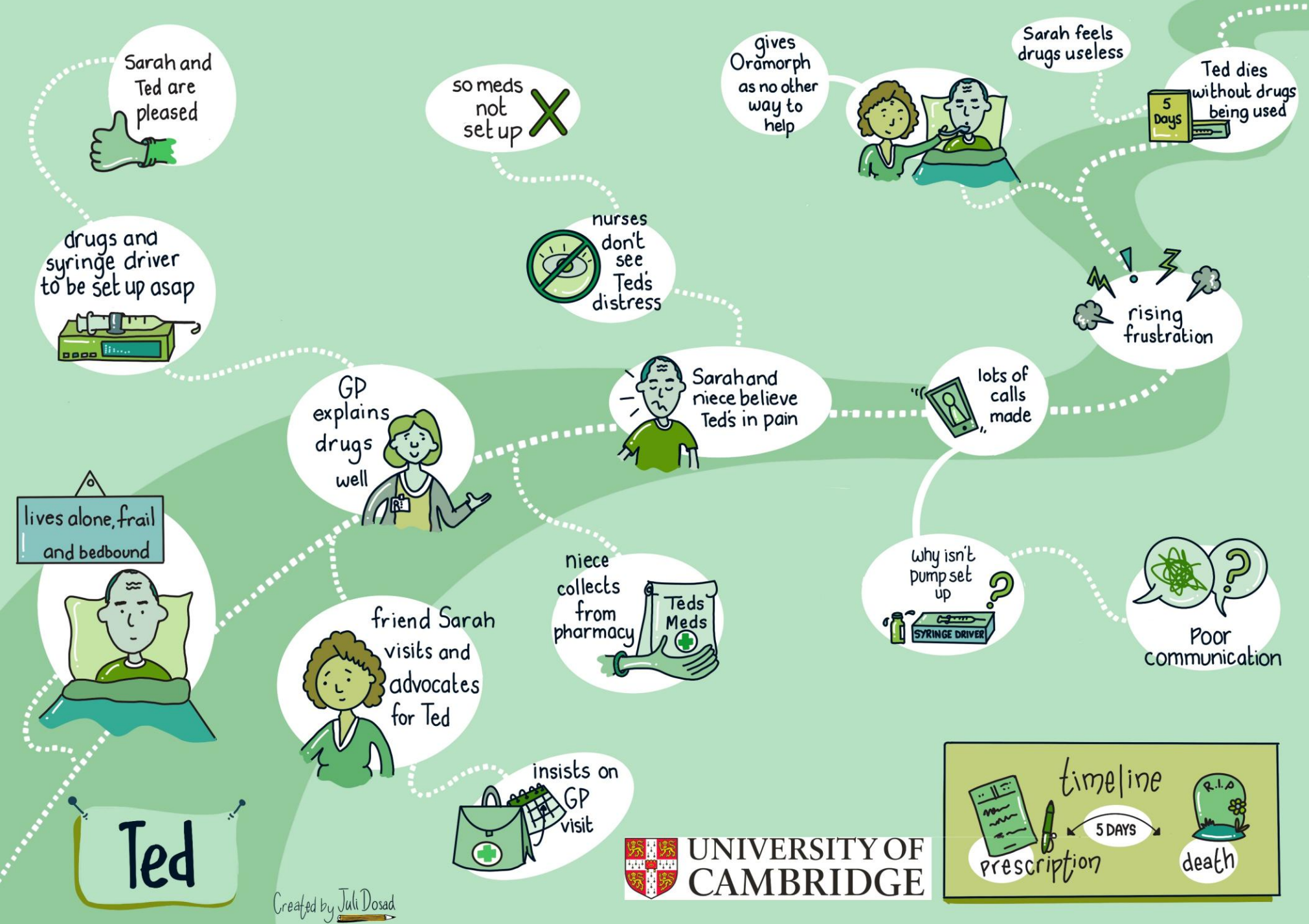


## Quality of information exchange

Ted:

- 91 years old, heart failure and frailty,
- lives alone,
- limited capacity
- Rapid deterioration
- AMs prescribed 5 days before death

Dr Rosanna Fennessy,  
Artemis Paterson, Dr  
Ben Bowers  
(rtf21@cam.ac.uk)



- **Perceptions of anticipatory medications**

*“I thought how easy it is for someone to just come in and bump somebody off. So, they stayed in the cupboard for purely an emergency only” - Amelia*

- **Quality of information exchange**

*“ We’ve phoned the palliative care nurses, but you go through to a call centre. We feel we’re not in the loop. Why has the pump not been done? it is very frustrating to see him like that and stuff’s there to make him more comfortable and nothing is happening – Sarah*

- **Ability to navigate healthcare systems**

*“Just too much messing about with phone calls, trying to get somewhere. It was one thing after another, 111, through to the chemists, chemist’s computers are down...”- Sue*

# Implications for practice

- Several 'pain points' for patients and carers when navigating AM care in the community which enabled us to identify areas for improvement –
  - Explanations of anticipatory medications – when, how, who
  - Optimising system transparency to facilitate navigation – clear pathways for contact and explanations
  - Tailoring input to individual patient's and informal caregivers' circumstances

Personas (real or amalgams) and experiential journey mapping - useful tools for incorporating patient voice and for comparing experience to intended pathways for different patient groups.

**Dr Rosanna Fennessy** [rtf21@cam.ac.uk](mailto:rtf21@cam.ac.uk)

**Acknowledgements: Artemis Paterson and Dr Ben Bowers  
PELiCam patient and public involvement group  
Dr James Ward and Prof J Clarkson  
Illustrator - Juli Dosad**

**This work is supported by the Wellcome Trust**

