Enabling Choice Supporting the Dying at Home

Palliative and End of Life Care Event: 23.03.2021

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Aims

Presentation: what we have learnt so far from an on-going research project.

Why this project?
What is the project?
What are the 8 areas of inquiry?
What will we do next?

Why this project? **Goals**

Best possible quality of life for the patient and their family
Good control of symptoms
To facilitate adjustment to loss
To facilitate and guide completion of “unfinished business”
A dignified death - in the patient’s place of choice.
Prevention of problems in bereavement
A partnership between the patient, carers and professionals
Affirms life and regards death as a natural process.

Life Story

- *Eddie's life*
- *When is the end the end?*

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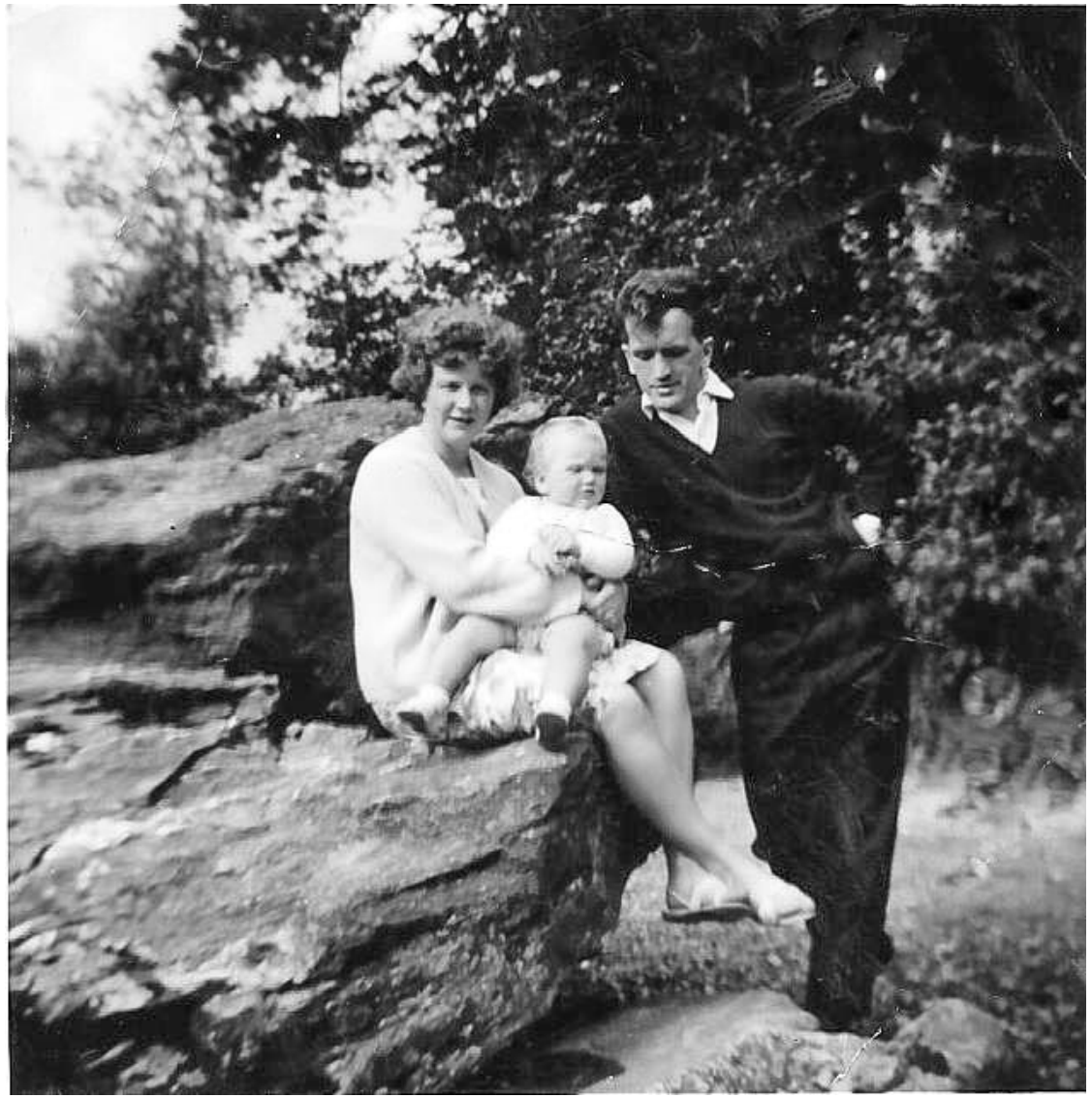

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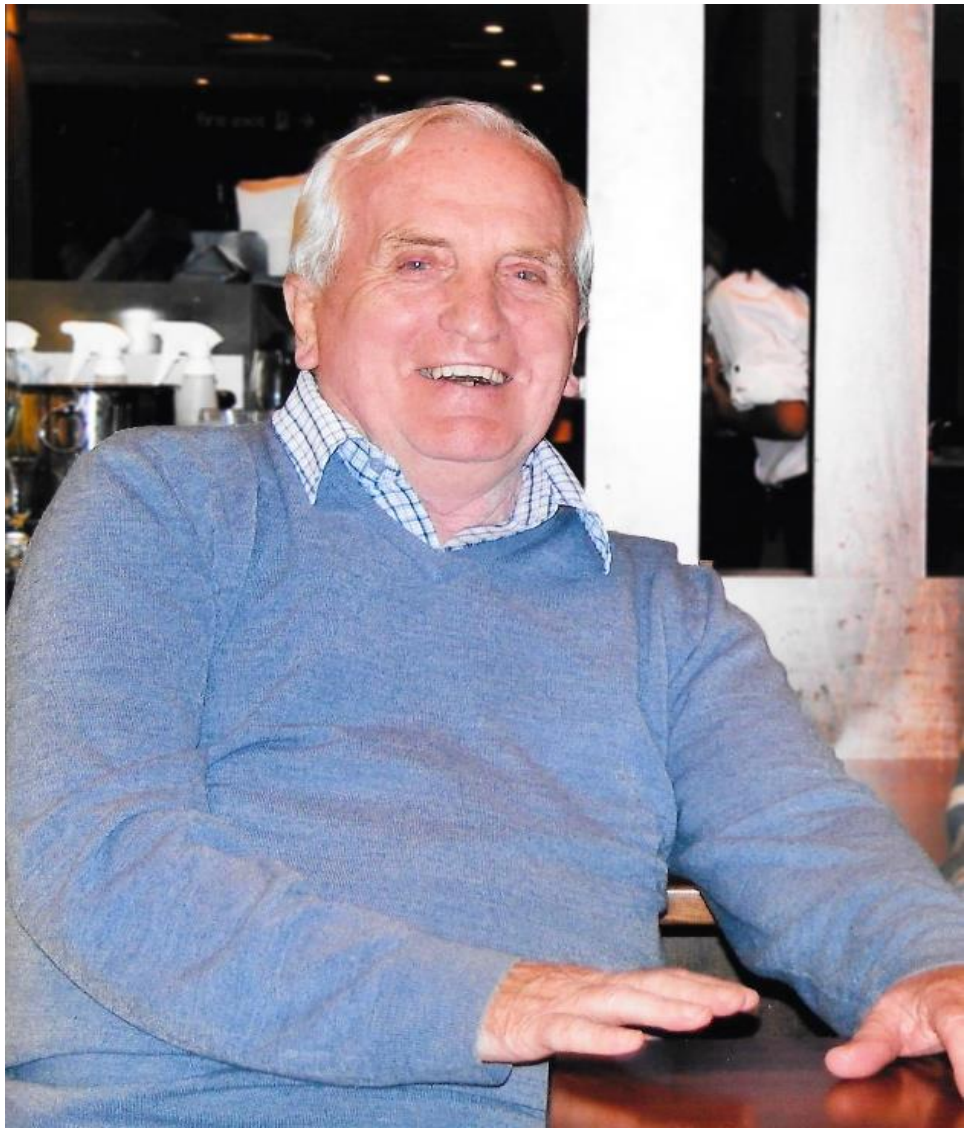

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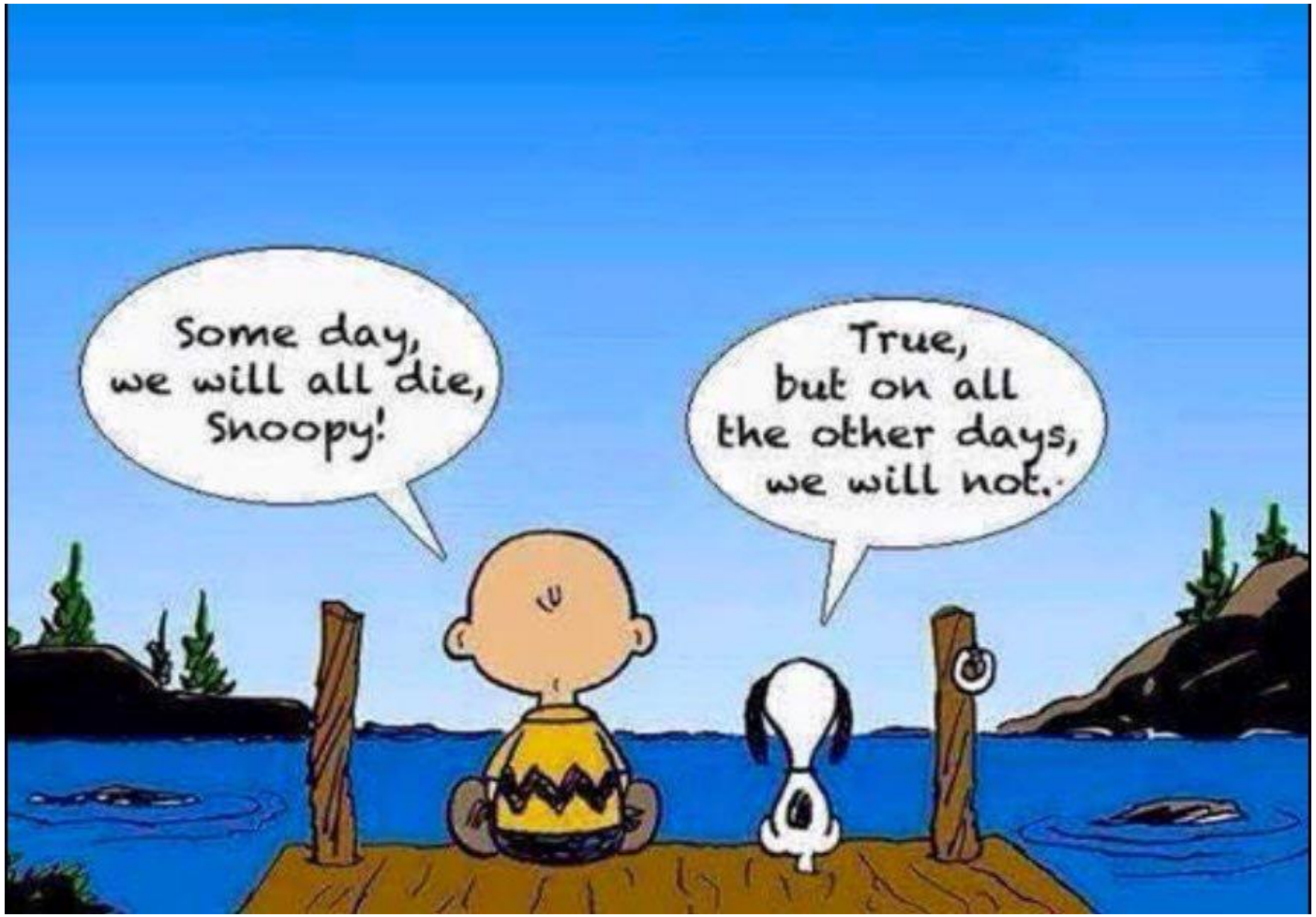
Two weeks before dying….


Some day, we will all die, Snoopy!
True, but on all the other days, we will not.

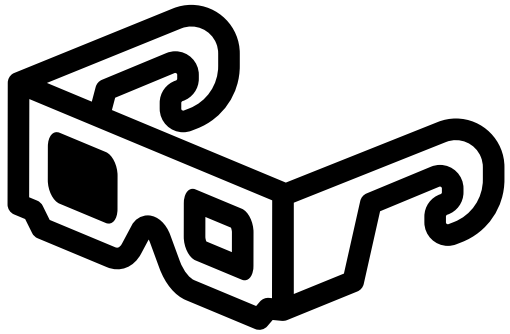
What is the project?

Realist Evaluation

Generative causation: *This* causes *that* and leads to *another*.

Context matters + so do individuals

Project: Rapid Response Service Models in End-of-Life Care: What Works, for Whom and in Which Circumstances?



Realist Evaluation asks us to wear 3D specs:
What Works, for Who, in What Circumstances?

Two sites x two years

Durham Rapid Response Service: 24hr
Northumbria Rapid Response Service: 10hr

Some differences in staffing and structure – both provide community end of life care to support people to die at home where that is their choice.

TO DATE: 1 of 3 planned research stages complete- P1 which was our 'theory gleaning' a lengthy process of preparation of initial 'hunches' or Initial Programme Theories (IPTs) of what is working, where, and why.

Ethics: HRA (REC), Local R&D, Marie Curie HQ

Developing Our **'Hunches'**

Begin by thinking in team about **how the RRS's might (not) work.**

Add in literature scoping, information from stakeholders, and these are grouped into areas and set out as: **if-then-because.** Written out in longer form these are **our 'hunches'.**

Then test these ideas with **people who use, work in, and work alongside, the service** in focus groups, interviews, and through collection of health economic data.

At the end, these will have been proven, revised, or entirely re-written in the face of the evidence, giving us detailed theories that explain **how, the RRS works, for who, why, and in which circumstance**.

IPT (CMMO Configuration)

Context

C

Environmental

Cultural

Structural

Mechanism

M

Resource

What does the prog/intervention provide?

Mechanism

M

Response

What is the (re)action to the C/M?

Outcome

O

What are the (un)intended short, medium, and long term consequences?

The Gunpowder Example

Pawson and Tilley (1997) use this example of a completed theory:

when a spark is introduced to gun powder, the chemical composition of gun powder (mechanism) results in an explosion (outcome). However, there are no explosions if the context is not right—damp conditions, insufficient powder, not adequately compact, no oxygen present, duration of heat applied is too short (context).

Children asking for a penny for the guy
Image credits

IPT1 Communications- an example:

IPT1 Communications

If patients and their families have the opportunity (**context**) to receive open and timely communication about the RRS at the end of life (what it is, what it offers, when and why) (**mechanism-resource**), they can make an informed decision about death and dying at home (**mechanism-reasoning**) and so will self-refer to the RRS (**outcome-1**), and/or post-referral (self or DN/GP) use the RRS, as opposed to another (emergency) service, in times of need (outcome-2), and admissions to hospital at end of life will be reduced (**outcome-3**).

Key point:

Open and timely communications, that are clear and appropriate, support people to engage with the RRS and provide information as service users move through transition(s) into end-of-life care and through end-of-life care period into death/post-death period.

Key points of our 8 'hunches' are:

Open and timely communications about end of life and the services available means people can use them

Referral routes into the services need to be clear and unconstrained

Services need to be culturally aware and responsive, or they might exclude people

Pain, multi-morbidity, fraility, or dementia might impact on service use

Where you live, in the city or in the countryside, can make a difference due to response times and community involvement.

The speed and form of response is important for service use.

A 24hr service is important to avoid the 'ordeal of the night' OR a planned service in the day can avoid 'the ordeal' without a 24hr service.

RRS staff need to demonstrate particular competencies and capabilities for service use

The capacity and experiences of friends, family, and carers at home matter for service use.

What’s next?

Interviews: **RRS staff, external HSCPs, carers, patients**

Health Service Use Log: **carers**

Produce and disseminate: **final theories**

And finally…

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Thanks!

Marie Curie
Care and support through terminal illness

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