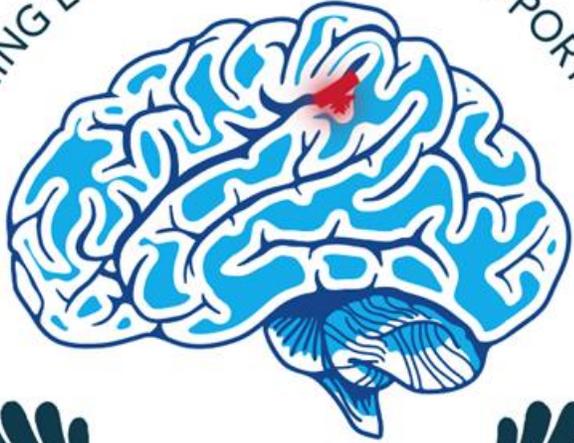


CO-DESIGNING LIFE AFTER STROKE SUPPORT PATHWAYS



CLASP

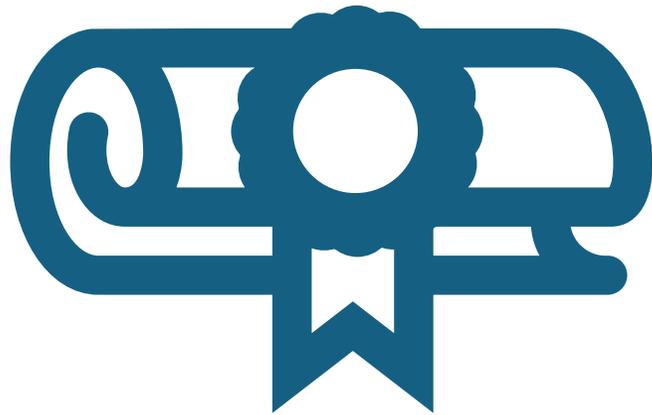
Life after Stroke

What do we mean?

&

How can we support it better?

Olive Lennon



Declarations

Funded research projects from the following:

Health Research Board, Ireland

Research Ireland / Science Foundation Ireland

EU MSCA Funding

University College Dublin Seed Funding

WP1



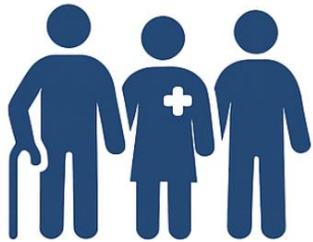
Conduct a rapid realist review of long-term support after stroke

WP2



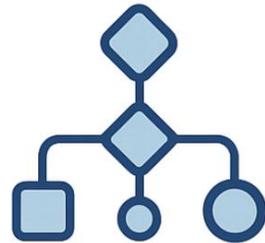
Determine prevalence and severity of stroke cases

WP3



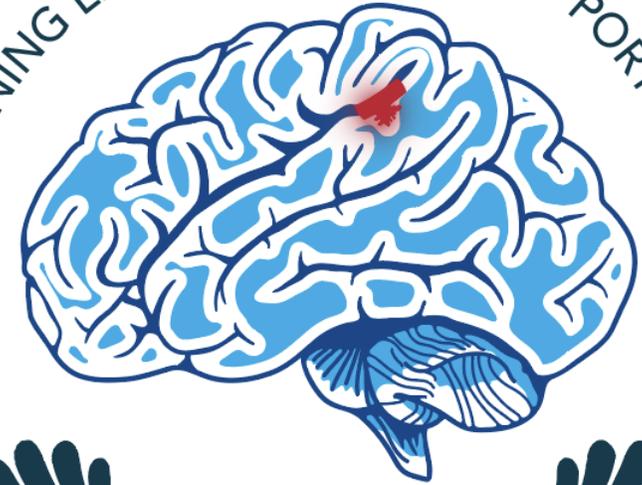
Assess the needs of people in the community

WP4



Co-design a care pathway with key stakeholders

CO-DESIGNING LIFE AFTER STROKE SUPPORT PATHWAYS



CLASP

Funded by a HRB Applied Partnership Award
Co-funded Irish Heart Foundation & HSE Stroke Programme

CLASP Research Team



Frances Horgan RCSI



Mary O'Neill RCSI



Eithne Sexton RCSI



Olive Lennon UCD



Martin Hally PPI



Fiona Bardon
PPI



Anne Moore RCSI



Sarah Murphy RCSI



Public and Patient
Involvement
Partners



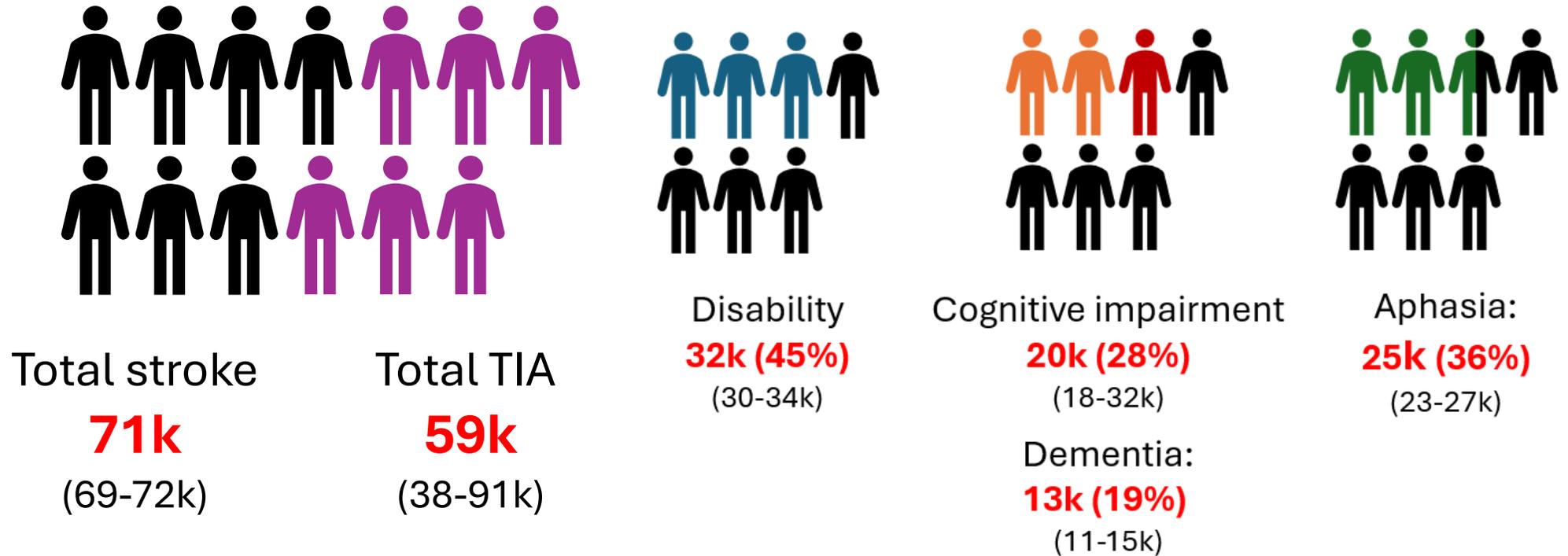
Martin Hally
Fiona Bardon



Introducing Martin –a CLASP partner with lived experience

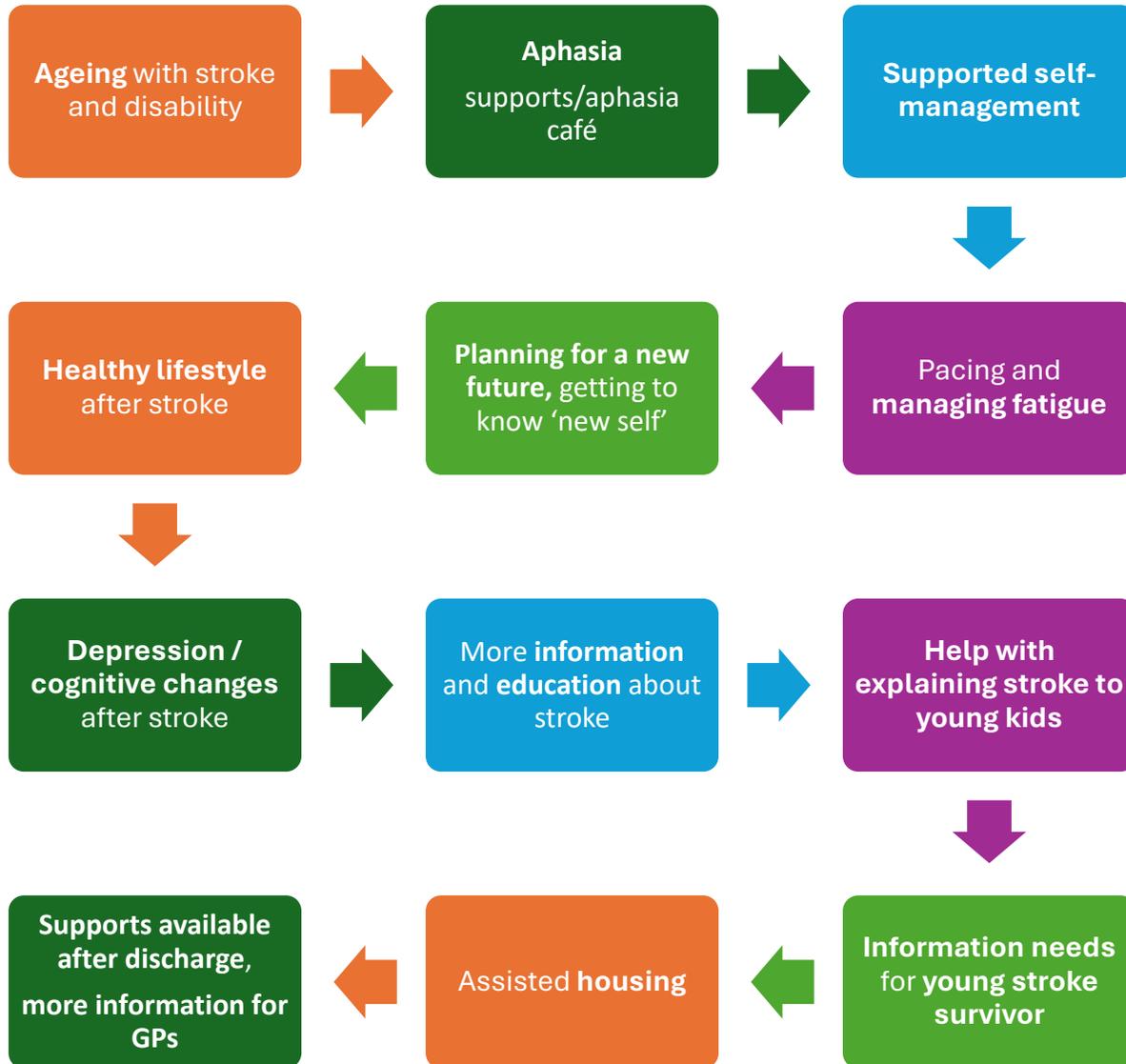


Stroke and TIA in Ireland 2022



Note: Each person represents 10k individuals. Uncertainty intervals in brackets

Stroke Survey: 436 responses



Fiona tells us what the term "life after stroke" means to her.



Fiona had her stroke when she was 33 years old.

She has been unable to return to her job as a teacher.

What do we mean by Life after Stroke?

Life Before



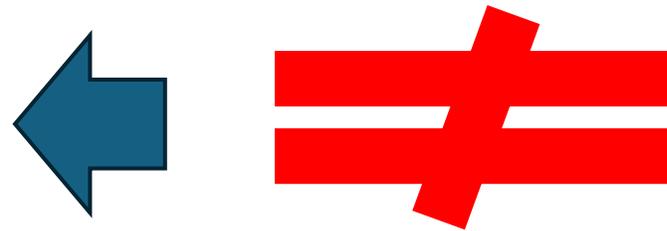
Stroke



Life After

Rehabilitation: “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment”.

WHO



Fiona shares some insights into the everyday life when first home from hospital



And some challenges in her life after stroke



**Fulfilment
&
Happiness**



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**Fulfilment
&
Happiness**

Self actualisation

I am Me

**Do you know your potential?
Are you self-aware / reflective?
Do you accept yourself?**

Esteem

I am Valued

**Do you feel respected and valued?
Do you feel like you are achieving something?
Do you have interests and hobbies?**

Love & Belonging

I am Accepted

**Do you feel loved?
Have you good family relationships?
Do you spend time with friends & social groups?**

SAFETY

I am Safe

**Are you medically stable?
Are you safe at home?
Have you sufficient income/financial security?
Have you adequate resources?**

PHYSIOLOGICAL

I am Secure

**Are you sleeping?
Have you food, shelter and water?
Clothing?**

Maslow's Hierarchy of Needs: Adapted for stroke

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Happiness**

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Clothing?**

Maslow's Hierarchy of Needs: Adapted for stroke

Fulfilment & Happiness

Self-actualisation

I AM ME

What gives me joy in my life?

Esteem

I AM VALUED

Would I manage to go back to work or to other things in my life?

Love & Belonging

I AM ACCEPTED

Is my family doing ok? Catch up with friends-what does it take out of me?

Safety

I AM SAFE

I can manage the basics for myself

Physiological

I am medically stable

I'm not going to die

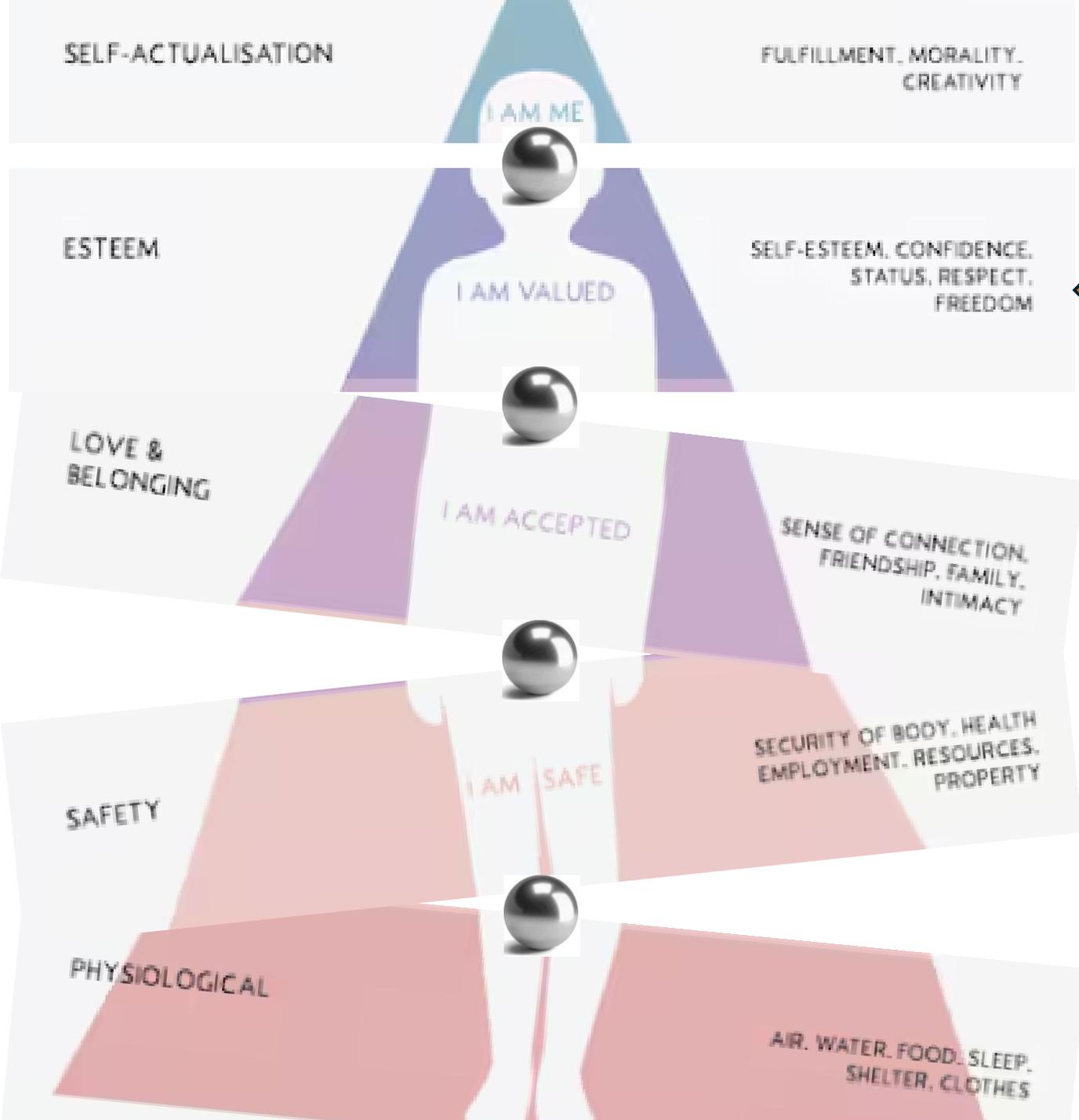


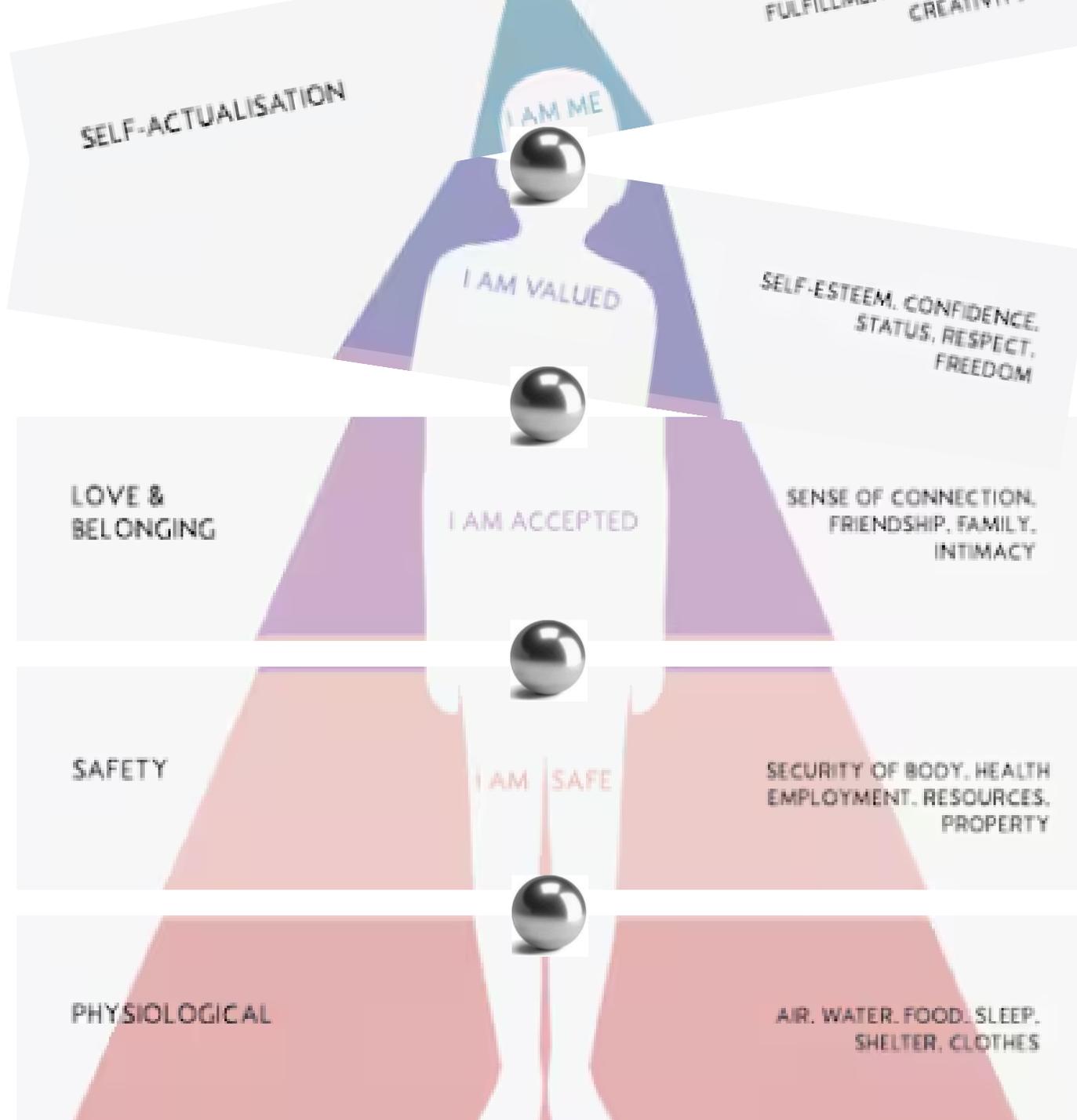


Retraining

Do you feel like you are achieving something?







Late onset of spasticity 4years on

Self-actualisation

Esteem

Love & Belonging

SAFETY

PHYSIOLOGICAL

Acute medical management

I AM ME

I AM VALUED

I AM ACCEPTED

I AM SAFE

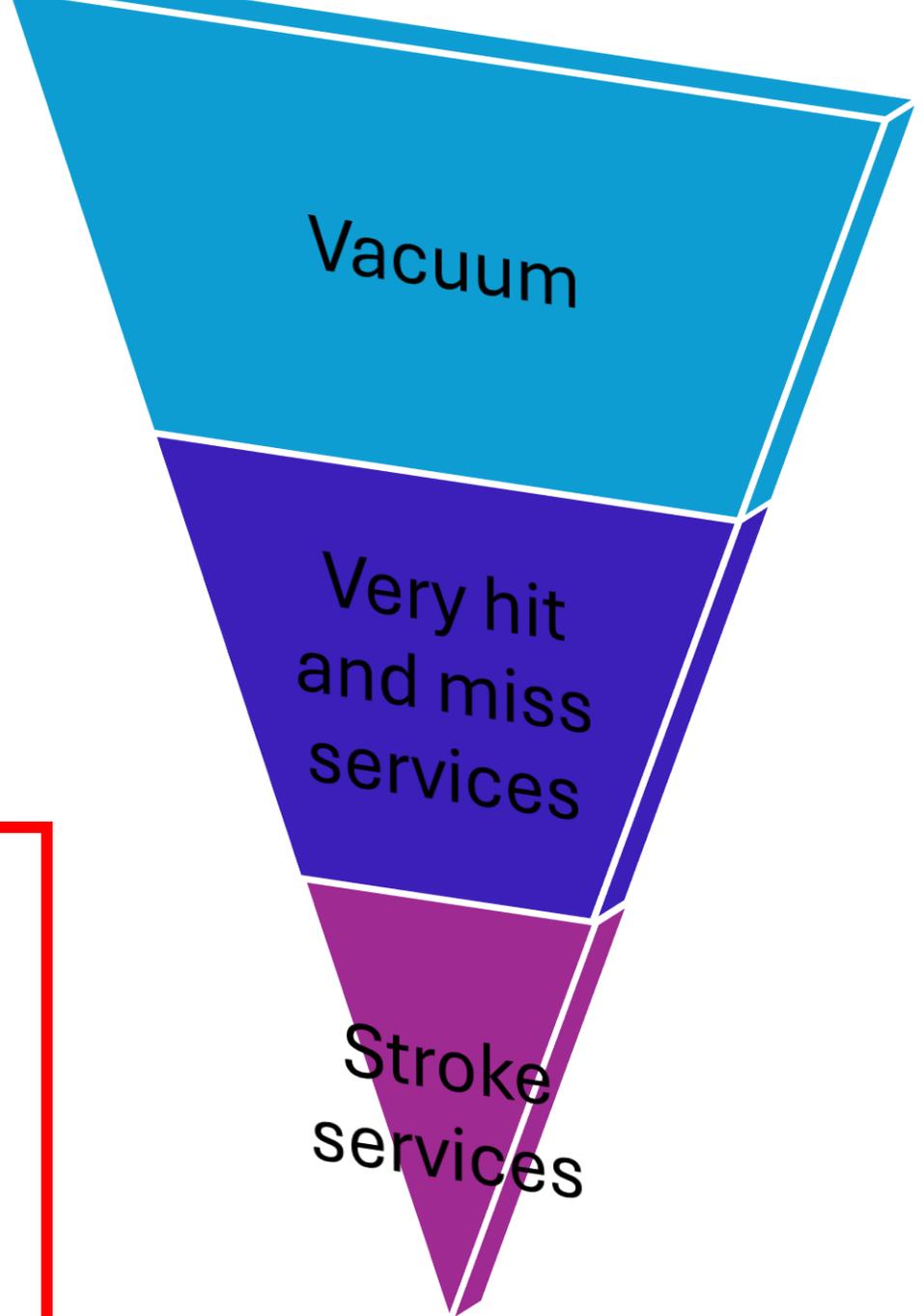
Fulfilment & Creativity

Work, Status, Self-esteem, Building confidence

Connection, Friendship, Family, Intimacy

Safe swallow, mobility & washing / dressing , basic care / falls prevention

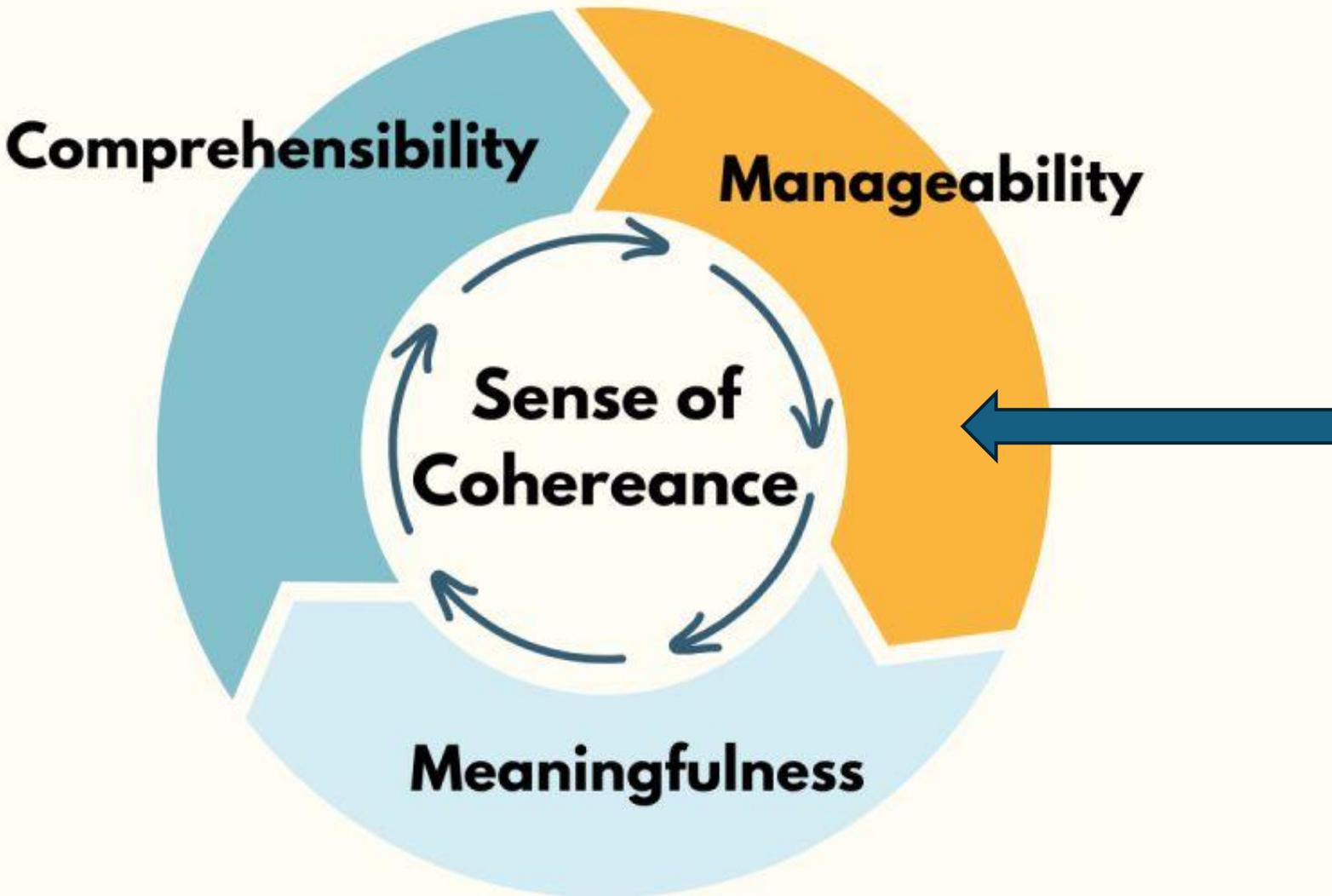
Hydration, nutrition

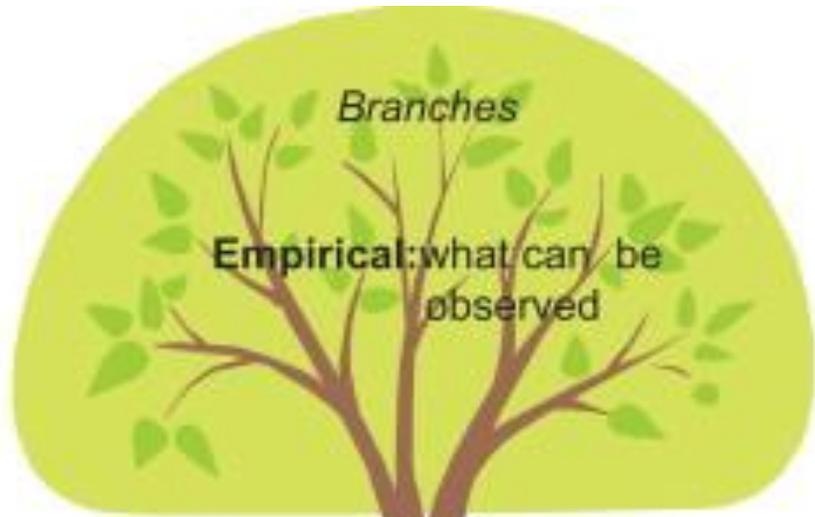


Salutogenesis



- Ability to understand stroke**
- Manage the effects of stroke**
- Find meaning in life after stroke.**

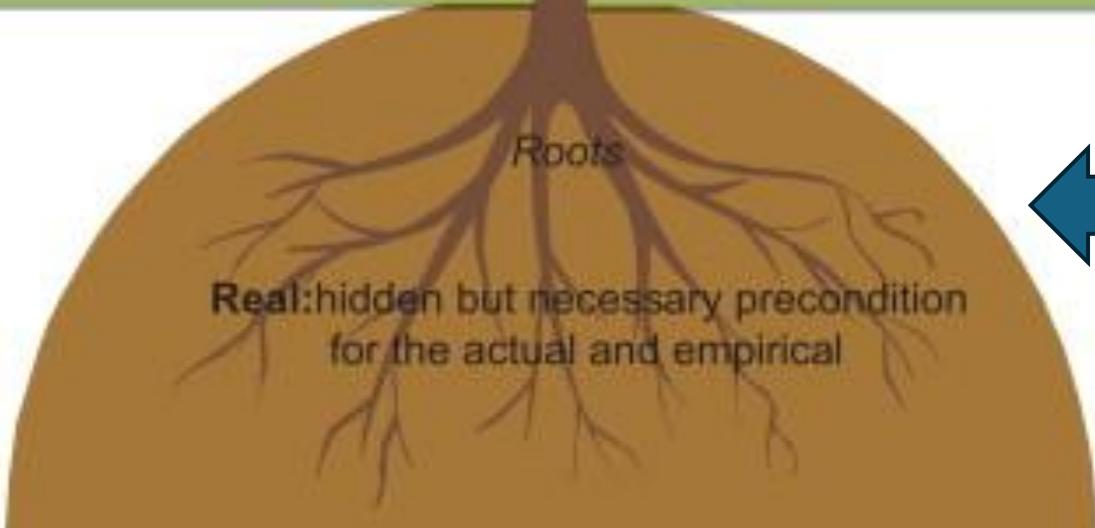




Empirical: what can be observed

Trunk

Actual: what is known but cannot always be seen



Roots

Real: hidden but necessary precondition for the actual and empirical

Initial
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Stage 6

Disseminate findings

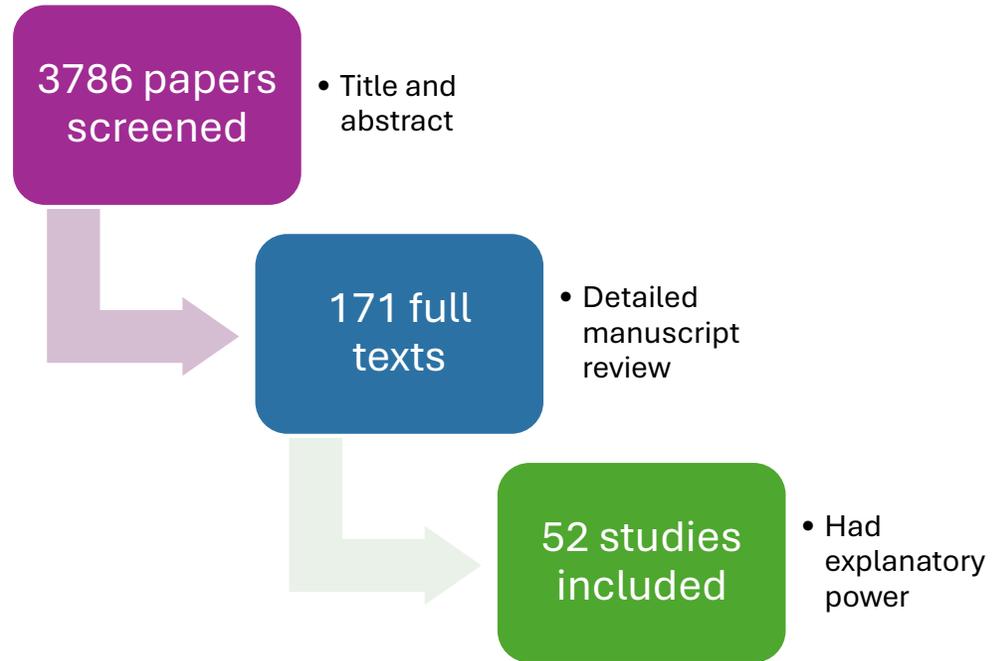
What nourishes someone to thrive in life after stroke?

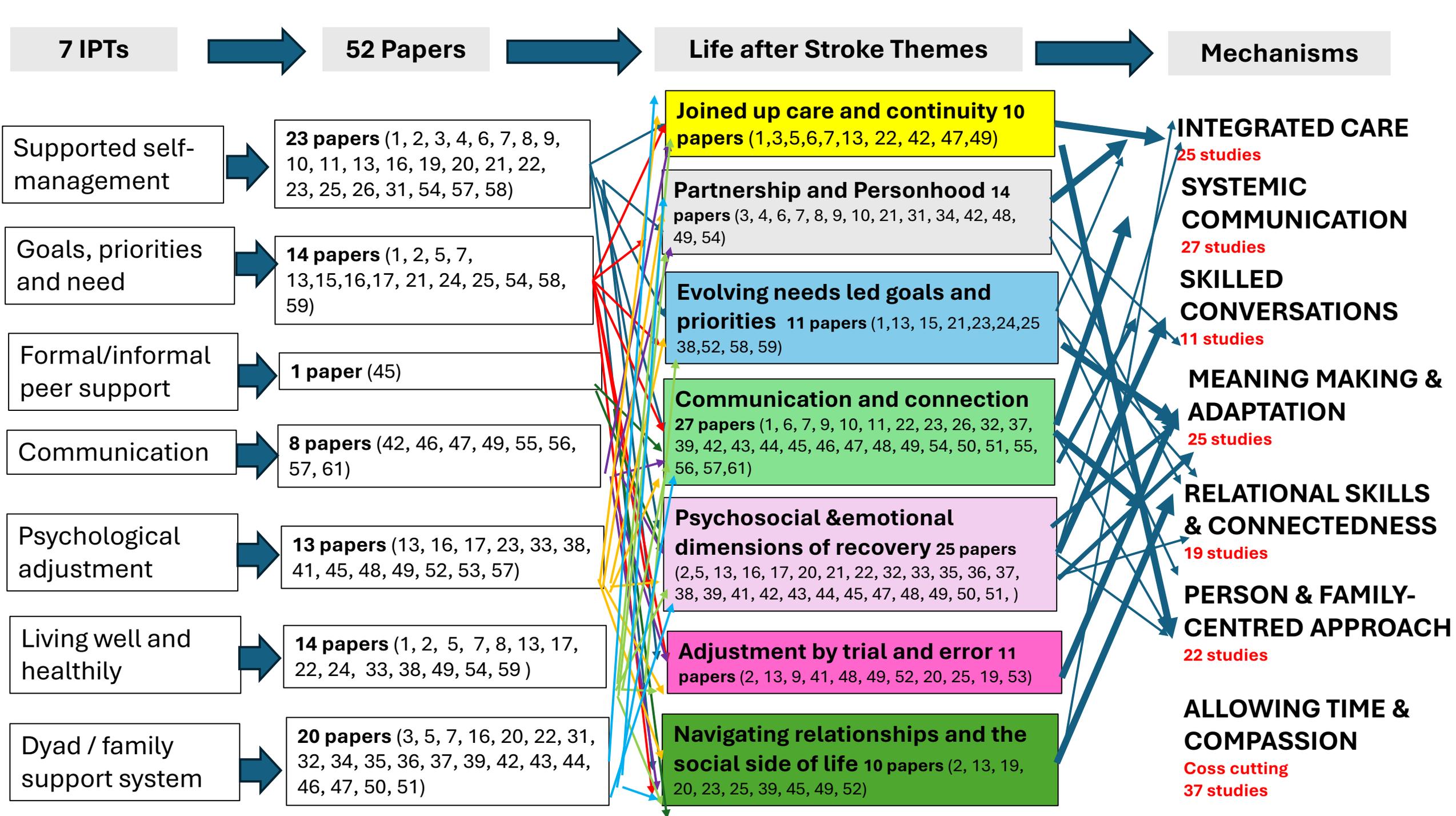


What a realist reviewer
looks like.



RAMESESPROJECT.ORG





BUILDING PROGRAMME THEORY

Context

Preparing for everyday life & moving on from structured rehabilitation

Getting on with a meaningful life after stroke & coping with its downs

Mechanism

An enabling health system

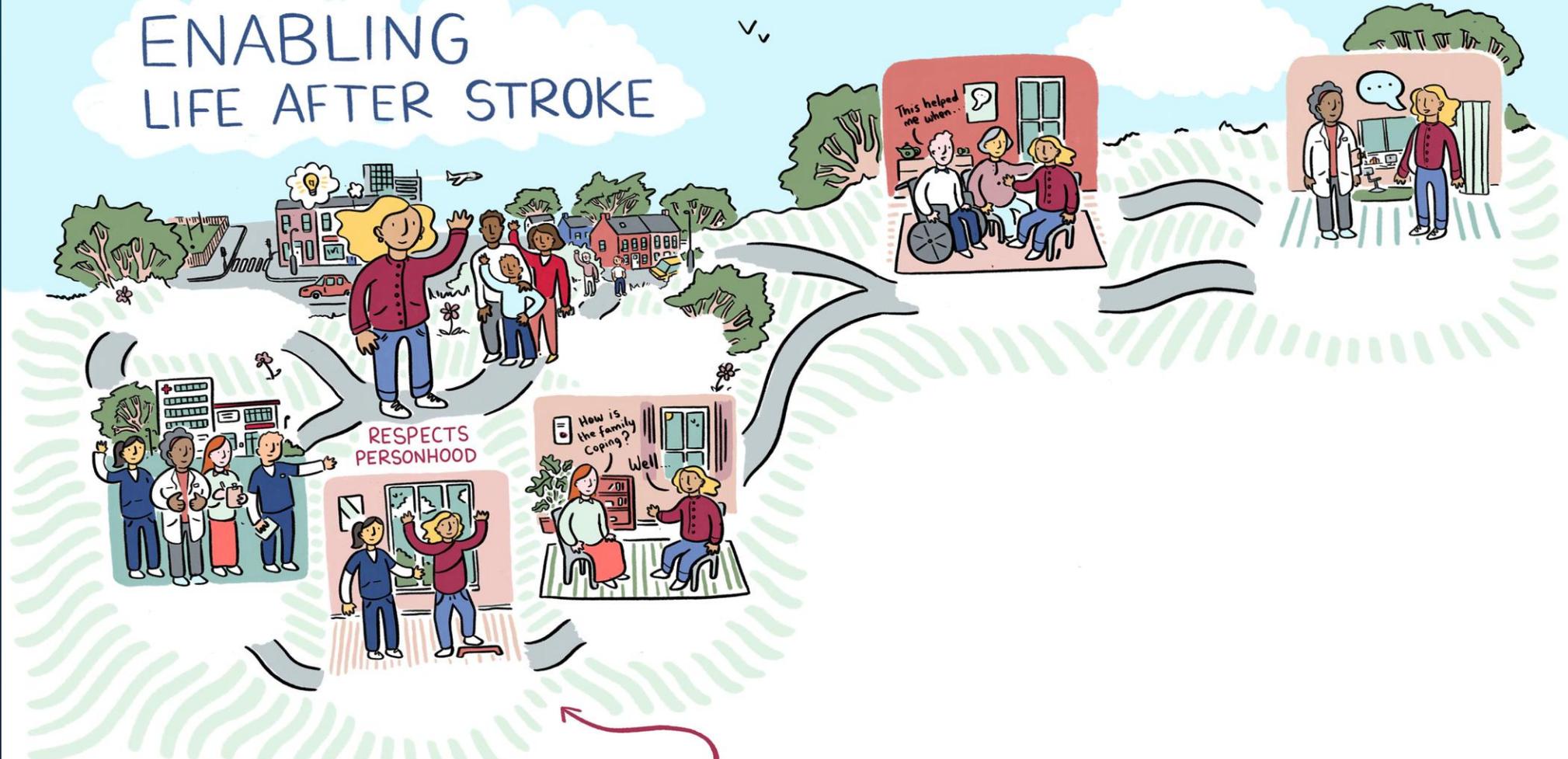
A PERSONAL JOURNEY

Outcome

The post-stroke world is understandable, that the resources required to cope well are available when required and that life has meaning.

Adjusting to a new normal and taking back control.

ENABLING LIFE AFTER STROKE



RESPECTS PERSONHOOD

How is the family coping?
Well...

This helped me when...

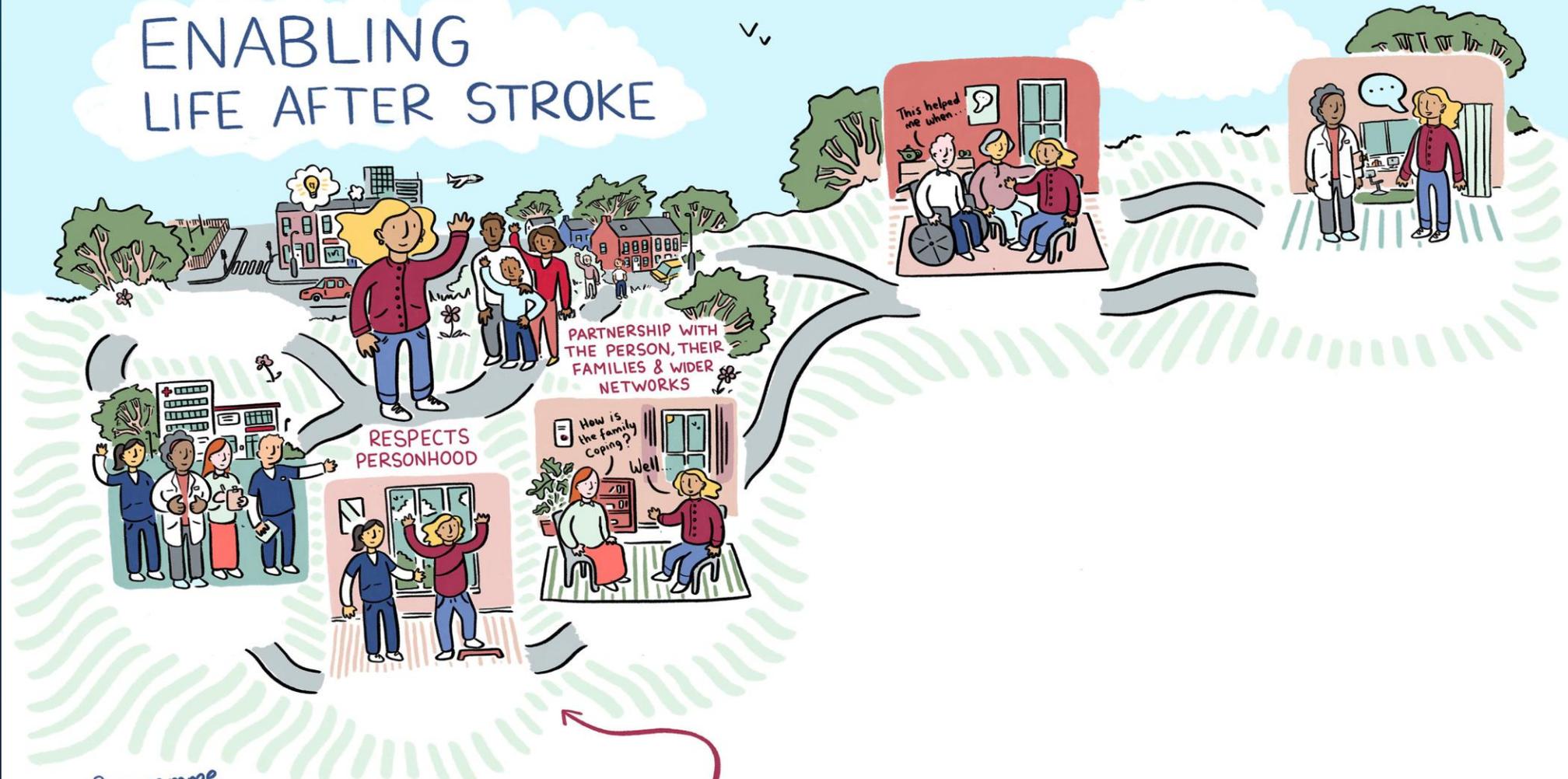
Speech bubble icon

Programme Theory 1

An Enabling Health System alongside Skilled Conversation & Systemic Communication

HELPS PROVIDE A SENSE OF COHERENCE IN A POST STROKE WORLD THAT IS UNDERSTANDABLE & HAS MEANING

ENABLING LIFE AFTER STROKE

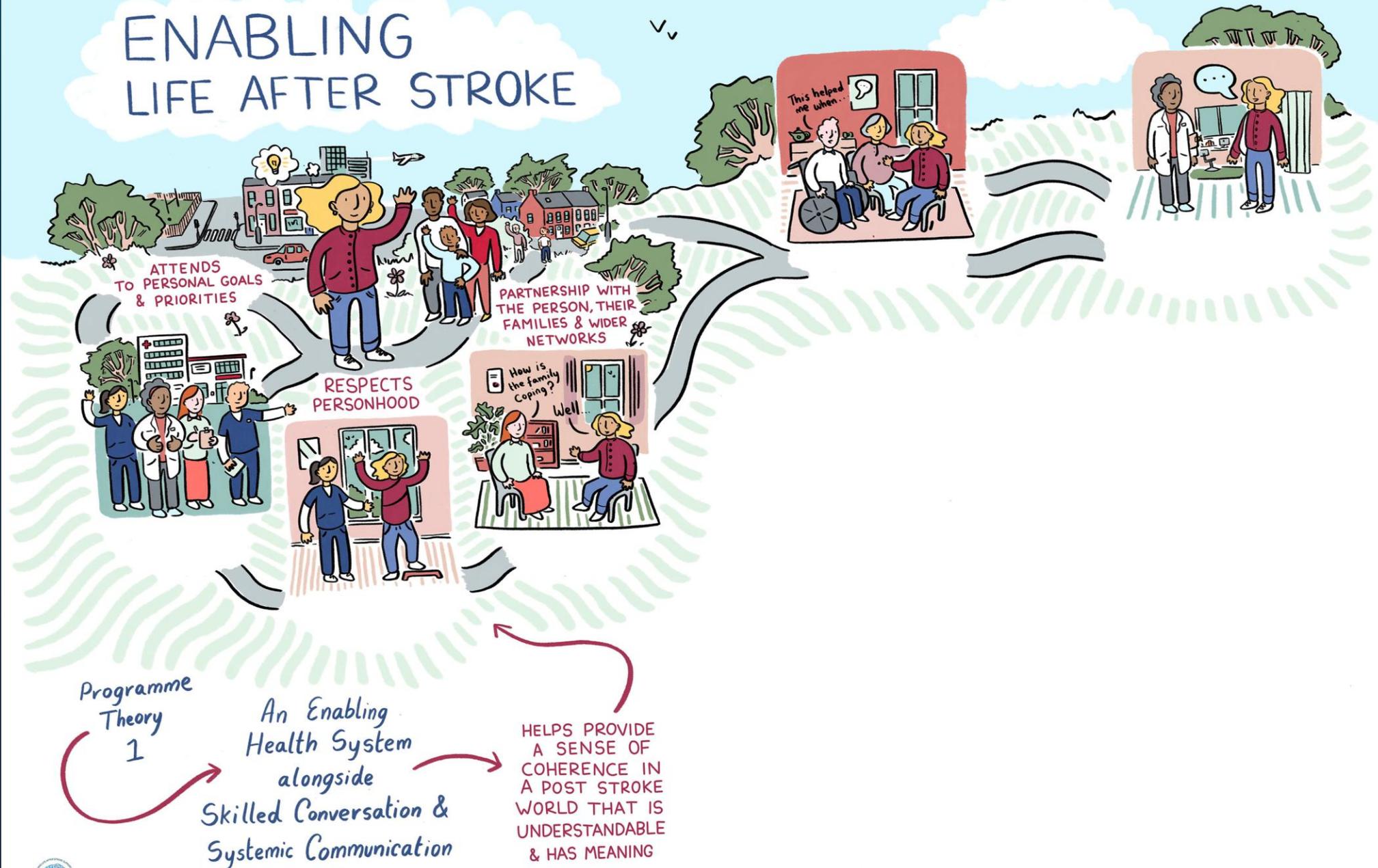


Programme
Theory
1

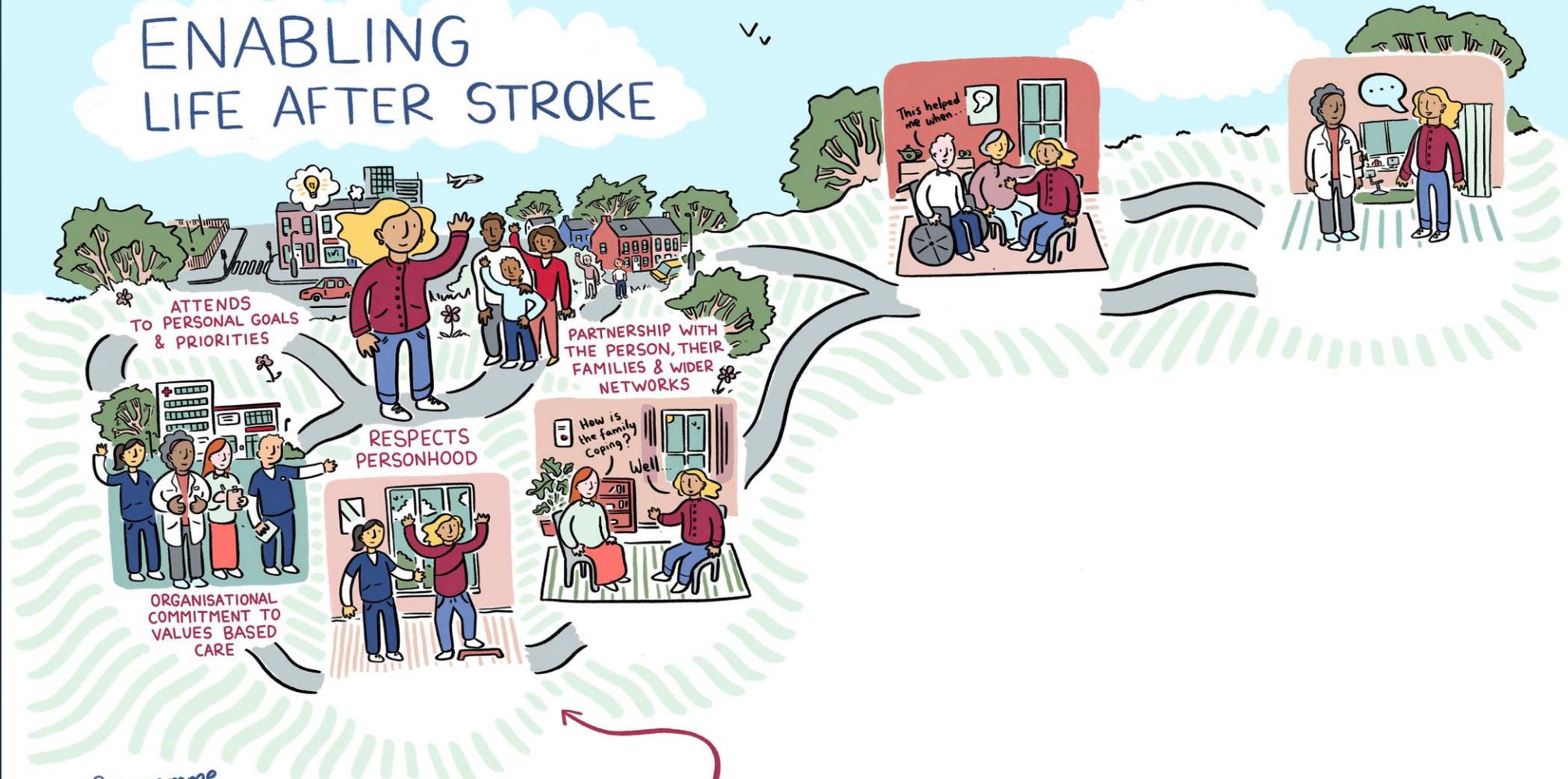
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ENABLING LIFE AFTER STROKE

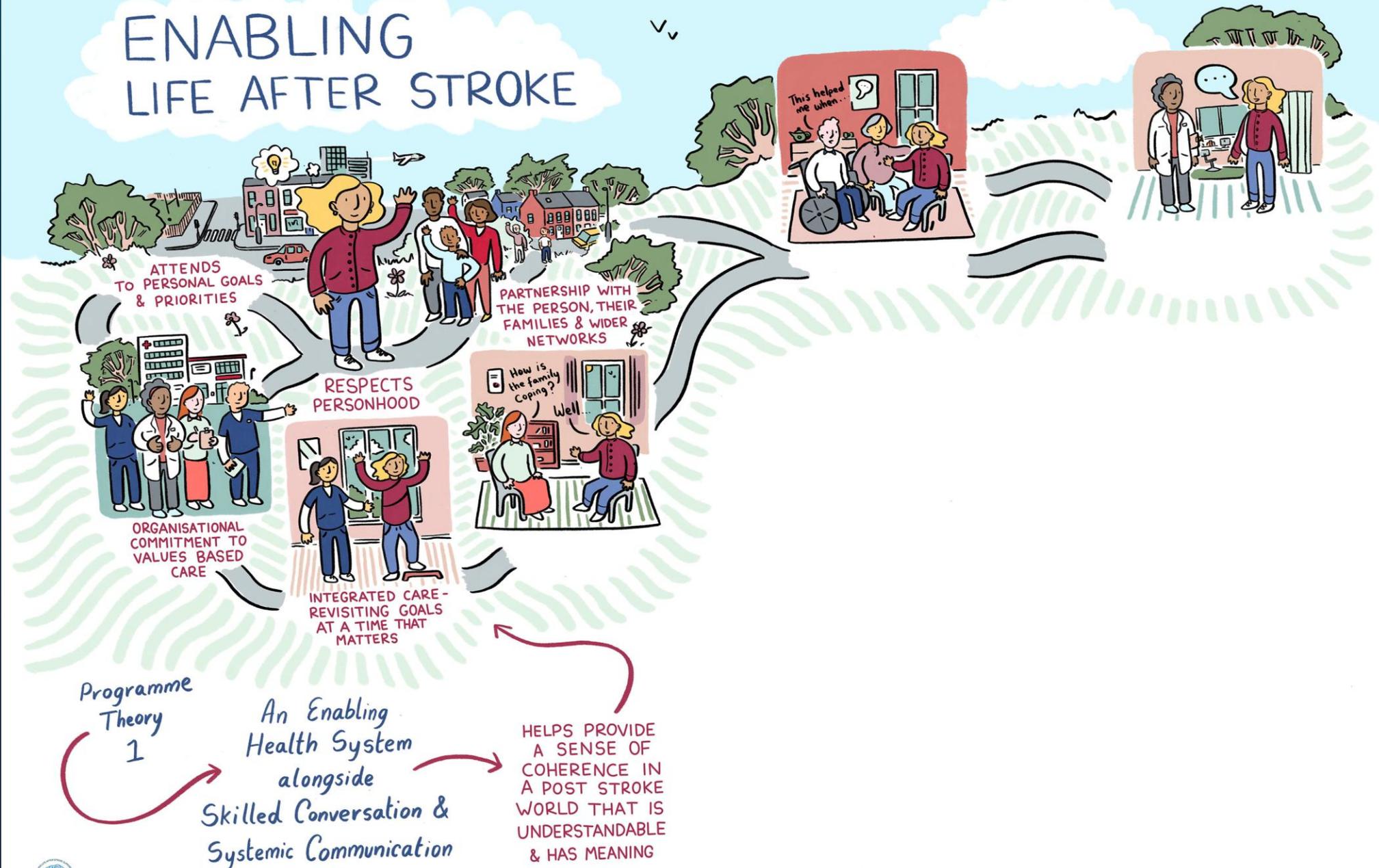


Programme
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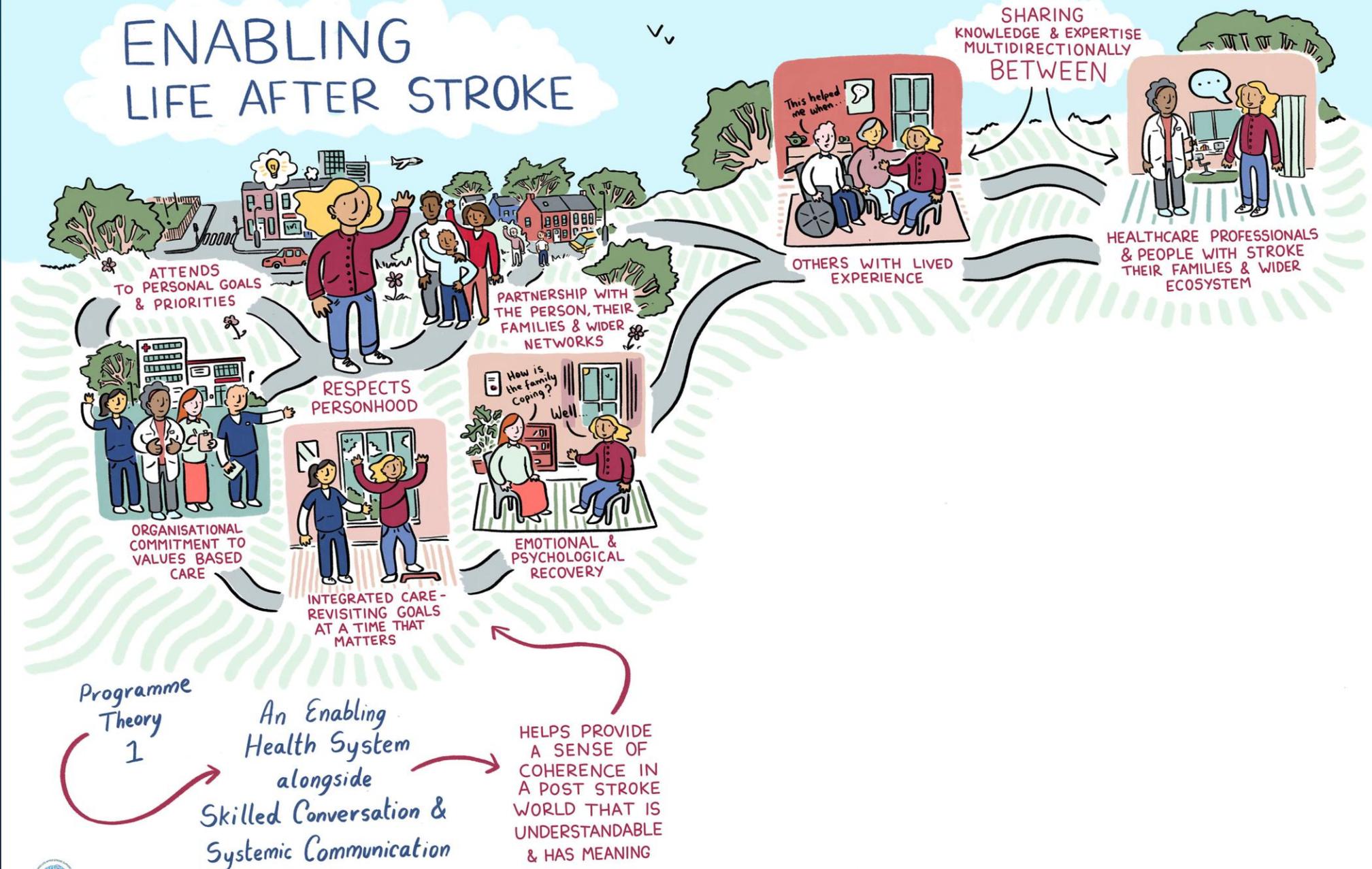


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ENABLING LIFE AFTER STROKE



ENABLING LIFE AFTER STROKE



SHARING KNOWLEDGE & EXPERTISE MULTIDIRECTIONALLY BETWEEN



Programme Theory 1

An Enabling Health System alongside Skilled Conversation & Systemic Communication

HELPS PROVIDE A SENSE OF COHERENCE IN A POST STROKE WORLD THAT IS UNDERSTANDABLE & HAS MEANING

Programme Theory 2

Time, Situated Learning, Reflection & Hope

HELPS WITH GETTING ON WITH LIFE AFTER STROKE, COPING WITH LIFE'S UPS & DOWNS. ADJUSTING TO A NEW NORMAL & TAKING BACK CONTROL.



ENABLING LIFE AFTER STROKE

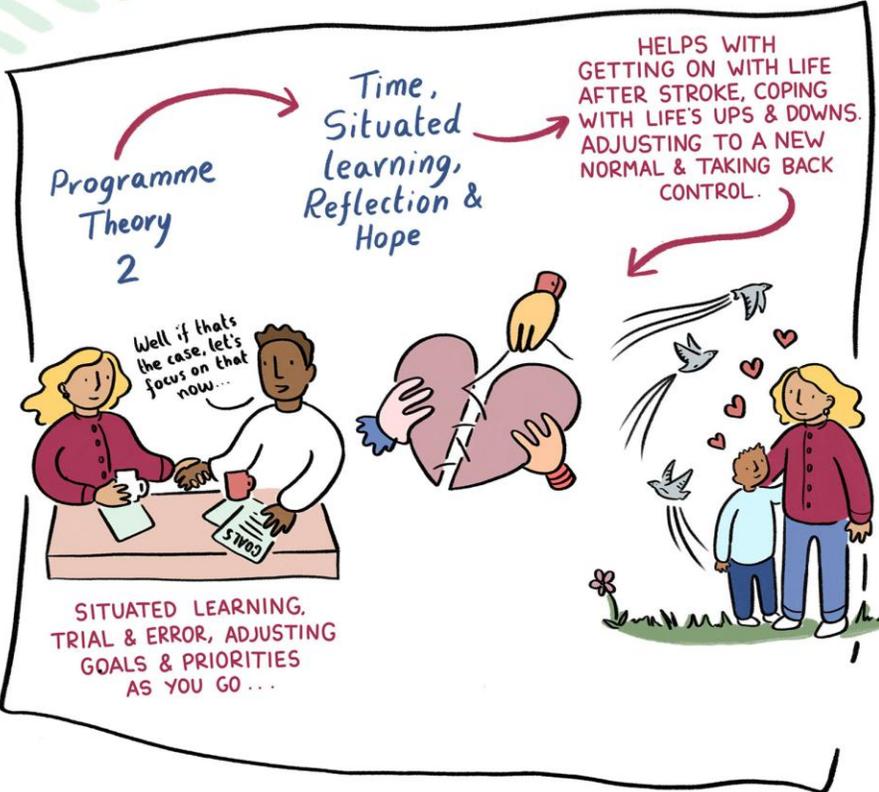


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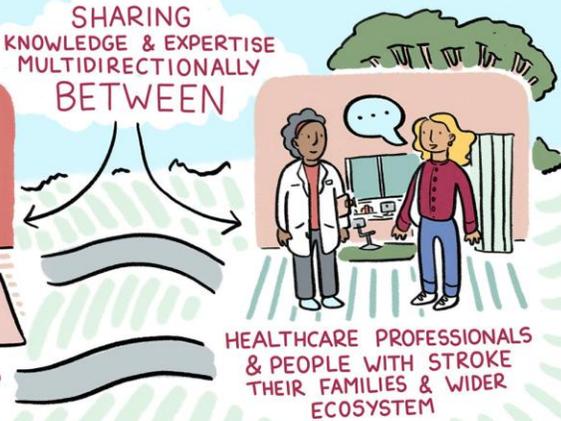
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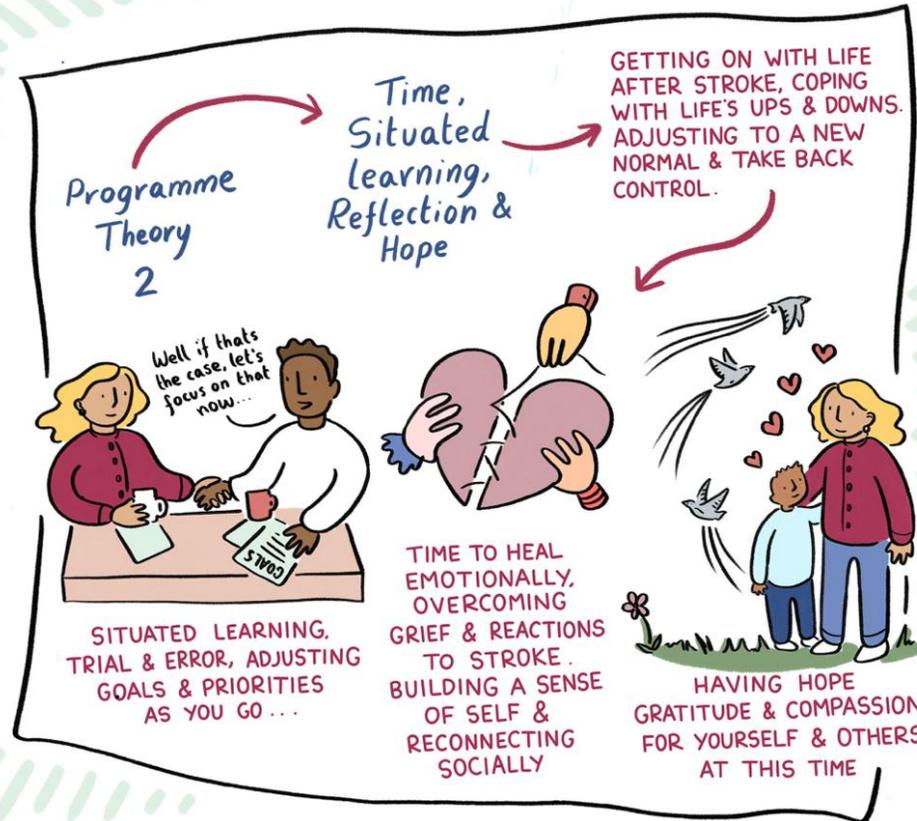
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HELPS PROVIDE A SENSE OF COHERENCE IN A POST STROKE WORLD



Mechanisms

HEALTH SYSTEM

DIFFERENT TIME ZONES



A PERSONAL JOURNEY

Martin tells us his thoughts on when life after stroke supports are needed



Acknowledgements



- **Funder:** Health Research Board Ireland APA-2022-019. **Co-funders:** Irish Heart Foundation, Irish Health Service Executive National Stroke Programme.
- **CLASP Research team:** Kathleen Bennett, Ronan Collins, Anne Hickey, Peter Kelly, Lorna Kerin, Thilo Kroll, Chris Macey, Molly Manning, Bo Norrving, PPI, Martin Hally, Fiona Bardon, ESO, SAFE Arlene Wilkie, Bernard O'Regan, Fiona Boland, Eithne Sexton, Anne Moore, Sarah Murphy, Richard Stables, Helen Gaynor, Jan Sorensen, Saoirse Duggan, Dr Geraldine O'Callaghan.
- **Irish Heart Foundation:** Chris Macey, Helen Gaynor, Helena Heffernan, Pauline O'Shea, Stroke Champions.
- **Croí team:** Annie Costello, Lisa Hynes, Libby Kineen, Beatriz Gomez Maestre.
- **HSE National Stroke Programme:** Ronan Collins, Ciara A Breen, Sinead Coleman, Fiona Connaughton.
- **HSE self management programme:** Mary Gowing
- **HSE Neurorehabilitation Programme Manager:** Ciara Lynch.
- Early Supported Discharge team members.
- Psychological Society Ireland: Aine Connolly, Marcia Ward.
- Wendy Moynan, Medical social worker. Aisling Creed, Senior Speech and Language Therapist
- StrokeLINK team Mater hospital Dublin
- iPASTAR and CLASP project PPI group members.
- Headway Ireland: Richard Stables, Megan Devereux, Lyndsay O'Toole, community manager, family counselling, vocational rehabilitation), ABI Ireland, National Disability Authority.
- Vocational Rehabilitation team National Rehabilitation Hospital Ireland: Fiona Ryan, Fiona Haughey
- IHF Young Stroke survivor group Dublin, Cork and Mayo.
- Members of the realist review expert stakeholder panel.
- Peer support team Peamount Healthcare: Nuala Crosse, Anne Kehoe
- Robyn Deasy Drawesome
- All of the mums, dads, and partners who met us to share their experiences of life after stroke. Thank you.

Co-designing a life after stroke support pathway

