

Creating services and a community where people live life well after stroke: a debate

Lived experience of recovery and reintegration after stroke

Core constituents required within a stroke service and the community for stroke survivors to live their lives well and not feel abandoned after rehabilitation ends

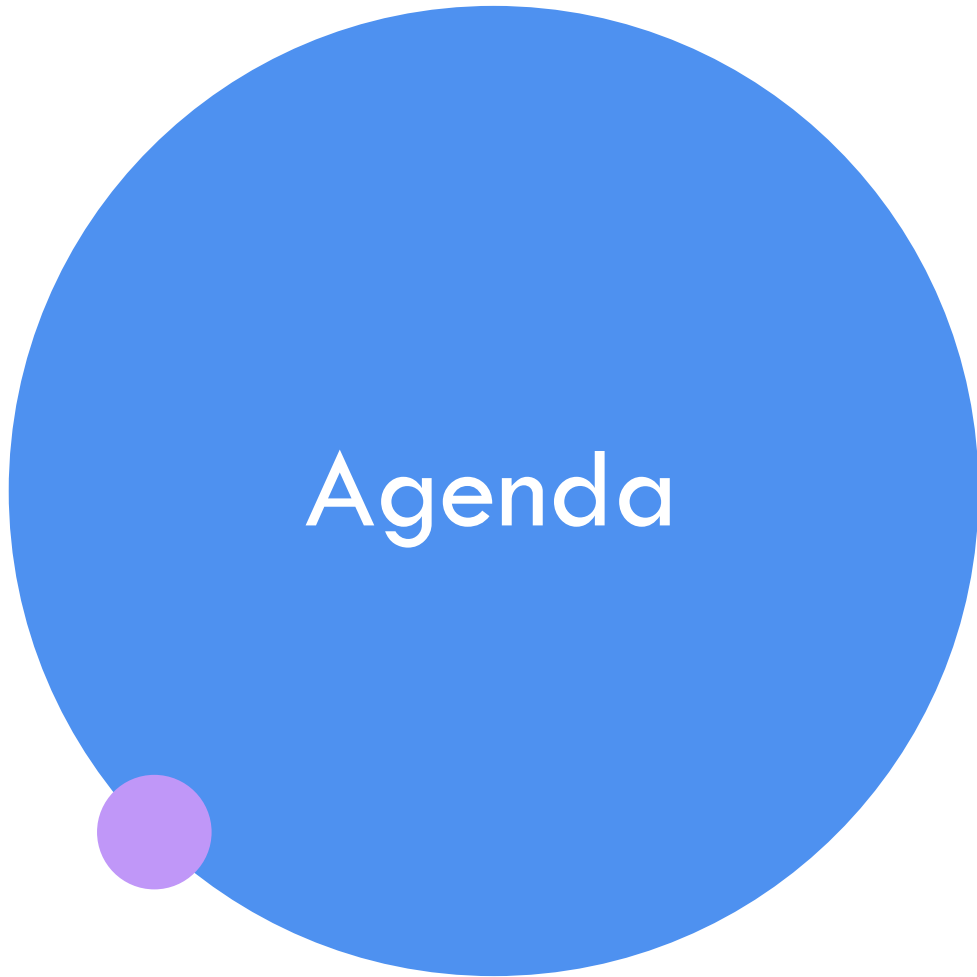
Debate with the audience: What should be in place to enable people to live well

Conclusion and call to action recommendations



Creating services and a community where people live life well after stroke: a debate

Fiona Jones



- Jim's story
- Nicola
- Marie
- Our call to action

As you listen to the presentations...

- Imagine....

You are in an elevator for 3 minutes with a billionaire who wants to change life after stroke

What are the 3 things you want them to remember when they step out the lift

That will make them give all their money and accelerate change in life after stroke across Europe



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Thank you

What's the one thing you will do after today?.....



Fiona



Jim

Creating services and
a community where
people live well after
stroke- let's talk!

Dr Nicola Hancock, , University of East Anglia, UK

The conversation...

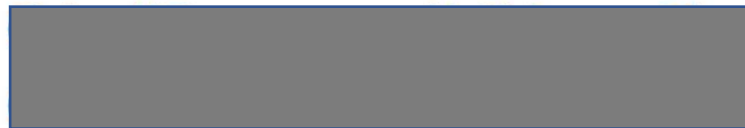
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Dr Nicola Hancock... · 04/12/2019 ...

Is it too much to dream of a day when a stroke survivor opens a conference and says 'Here is my story. I did NOT feel **abandoned** when I got home' ?


[#UKSF2019](#) [@UEA_Health](#)



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Dr Nicola Hancock... · 29/07/2019 ...

Replying to  and 3 others

An approach which meant that no-one ever has to say again, 'When I left hospital...(rehabilitation unit... community rehabilitation services..) I felt **abandoned**' Optimal time for support is not the same for everyone. We conform to the system on offer. Perhaps we shouldn't...

3 3 9

How it's going

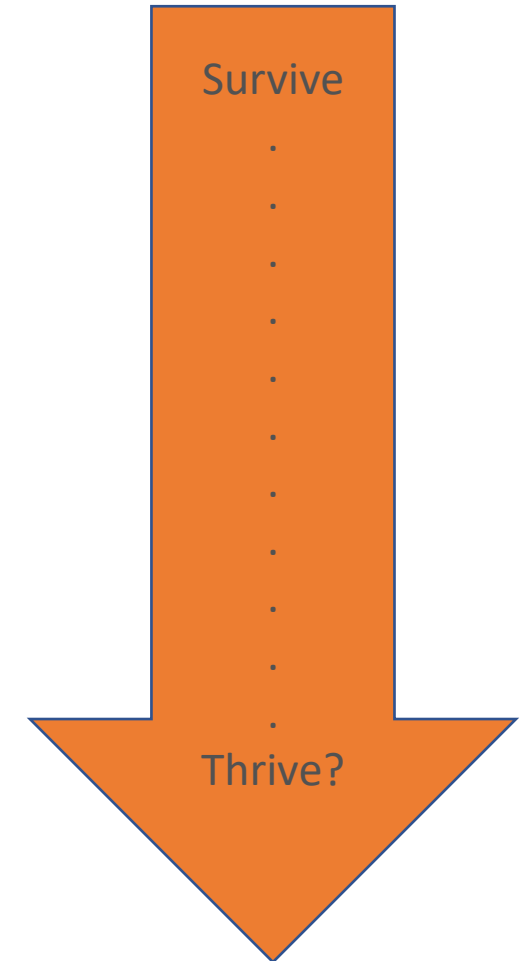
Urgent and immediate care – huge gains

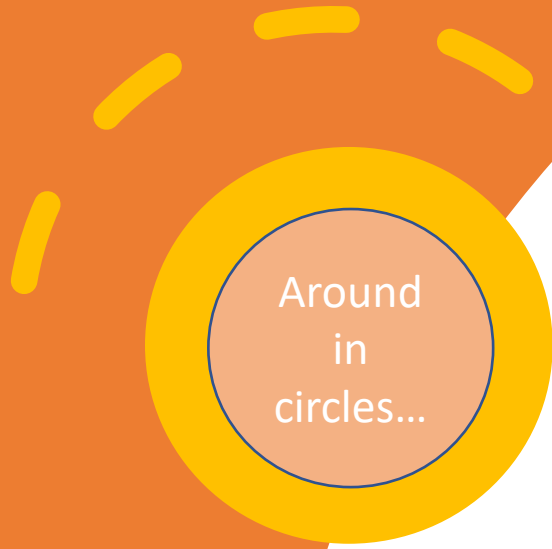
Evidence base expanding all the time, clear evidence-
rehabilitation works, incredible professional expertise

Less clear evidence of *translation/implementation to
clinical practice* e.g. of technologies

Policy drivers (UK) for personalised
care/rehabilitation; user-centred approaches to
interventions and services

And yet- people still report feeling
abandoned-why?





Around
in
circles...



A continuum of care

Addressing the sense of abandonment serves not only people with stroke, but their whole community. An individualised approach, but one that impacts across a society?

And in doing so, health and social care staff are supported to deliver the job they trained to deliver- bringing staff closer to their professional ideals, enhancing professional identity and empowering future change¹



¹Hancock, N.J., Houghton, J., Jones, F. Integrating an approach to personalised self-management support in stroke and neurorehabilitation service contexts: People1st- a quality improvement initiative. *Disability and Rehabilitation* 2022, <https://doi.org/10.1080/09638288.2022.2127930>



Harnessing technology for a 'living well after stroke' toolkit

Promise and opportunity ^{e.g. 2,3}:

- Enhancing patient interest and motivation; reducing feelings of 'abandonment?'
- Providing opportunities for self-management
- Widening participation in rehabilitation activity in home & community settings

Some parallels with supported self-management:

- Shared decision making and goal setting
- Identifying barriers, problem solving
- Tailored support
- Education about the effects of practice and feedback

²Demain S, Burrige J, Ellis-Hill C, Hughes A-M, Yardley L, Tedesco-Tricas L, Swain I. Assistive technologies after stroke: self-management or fending for yourself? A focus group study. *BMC Health Services Research* 2013; 13:334. DOI: [10.1186/1472-6963-13-334](https://doi.org/10.1186/1472-6963-13-334)

³Clark, D., Dean, G., Bolton, S., Beeson, B. Bench to Bedside: The technology adoption pathway in healthcare. *Health and Technology* 2020; 10(537-545)

A call to creativity and action

A call to disrupt...?

Our shared voices and visions; our passion and compassion

Our knowledge and expertise

Our technologies

Our mission to thrive, to live well after stroke

To Survive

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And then
to

Thrive

Acknowledging

- Professor Fiona Jones for the invitation and our shared vision
- Rebecca Rayner, UK Physiotherapist for recent clinical insights, UK
- Colleagues in the AbiliTec and ABIRA groups at and around UEA



Creating services and a community where people live well after stroke - let's talk!

... about the environment!

Marie Elf, Dalarna University



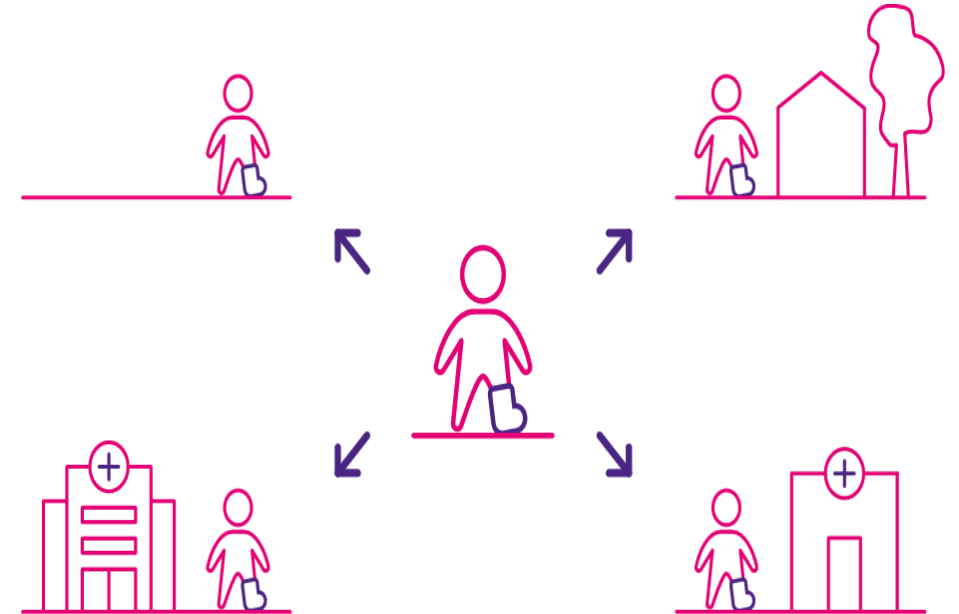
Environmental Factors in Rehabilitation

Accessibility, Social
Support, Safety

And opportunities

Principles of health services

- Should be provided close to the population.
- Should primarily be given as outpatient care.
- Can be provided in a place other than a care facility.
- The home is a place for rehabilitation



Environmental Integration Views: Perspectives of Persons

“I go out and pick up just a couple of sticks; I do that all the days”

Underutilized

No, I'm not using bus, but she who ... the physiotherapist, says I have to test. We only tested taking a bus from here and to the centre once.

Expert-centric

Yes, they had a program with certain themes, they regularly added new exercises. And then they asked, do you think it's okay to do this.

Standardized

...we had no planning, I was advised ... and received information from the start; I knew what was going on ...

Uninvolved

Contradictions

The practitioner said that the environment was important and that they included it in the rehabilitation ...

The patients said that activities they had performed before stroke such as gardening were put on pause

The patients had seldom been outside the local environment and when they had it, it was for visits to the health care

Let's be person-centred!

- Person-centered care must include environment, and shared decisions ensure adaptations meet individual needs
- Rehabilitation need to reorient its focus from functional recovery to support for the person's living situation, including their environment
- Home and neighborhood environment can challenge a person's security

Promises and Opportunities

Rehabilitation must consider the impact of the environment on recovery and well-being

Factors such as community resources, social support, and safe public spaces should be considered.

A holistic approach to rehabilitation can address individual needs within the environment

Inclusive community planning must involve people with experiences, policy makers, and healthcare professionals to create a supportive and accessible environment for people after stroke