

# Getting back to life after stroke

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# The Issue

“The experience of stroke really starts when a patient leaves hospital.... On discharge patients have to adjust suddenly to the impacts of the stroke on their life at home”

National Audit Office Report  
November 2005

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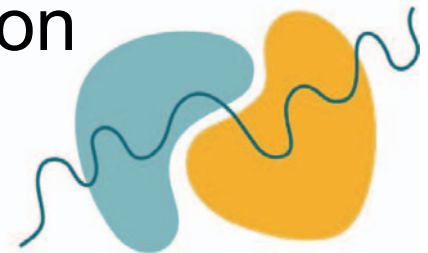


# Getting back to life - a journey from impairment to adjustment?

People living with stroke say that **recovery**

- has no neat move from one stage to another
  - good days/bad days, ‘adjusted days’/questioning days
- is not unidirectional
- is not predictable from one person to the next
- is not finite
- requires flexibility from, and coordination between, services

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# So - what this talk is about

- the challenges of supporting recovery after stroke
- a framework to underpin the process of getting back to life after stroke
- ideas for ways to support getting back to life after stroke

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# Lots of evidence of need for improvements to long-term support services

e.g.

- National Audit Office Report 2005
- Public Accounts Committee Report 2006
- Healthcare Commission Survey 2006
- Royal College of Physicians National Sentinel Audit 2006
- Many research studies

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# What do they suggest is needed?

- Information, information, information
- Integration, integration, integration
- More wide ranging and creative ways of providing support, for longer

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So, lots of evidence.....

....but few examples in practice of how to achieve this – why?

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# Challenges for service & opportunity providers

-1-

Scale of the problem:

- More people will survive stroke
- Even 'minor' strokes can have major life impacts
- Partners & families often need as much support as the person who has had the stroke

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# Challenges for service & opportunity providers

-2-

Support needs to be:

- flexible: one size doesn't fit all
- timely: right support at right time
- durable: accessible across a lifetime with stroke
- co-ordinated: giving a sense of liaison, handover, what comes next
- collaborative: doing *with* not doing *to*

# Challenges for service & opportunity providers

-3-

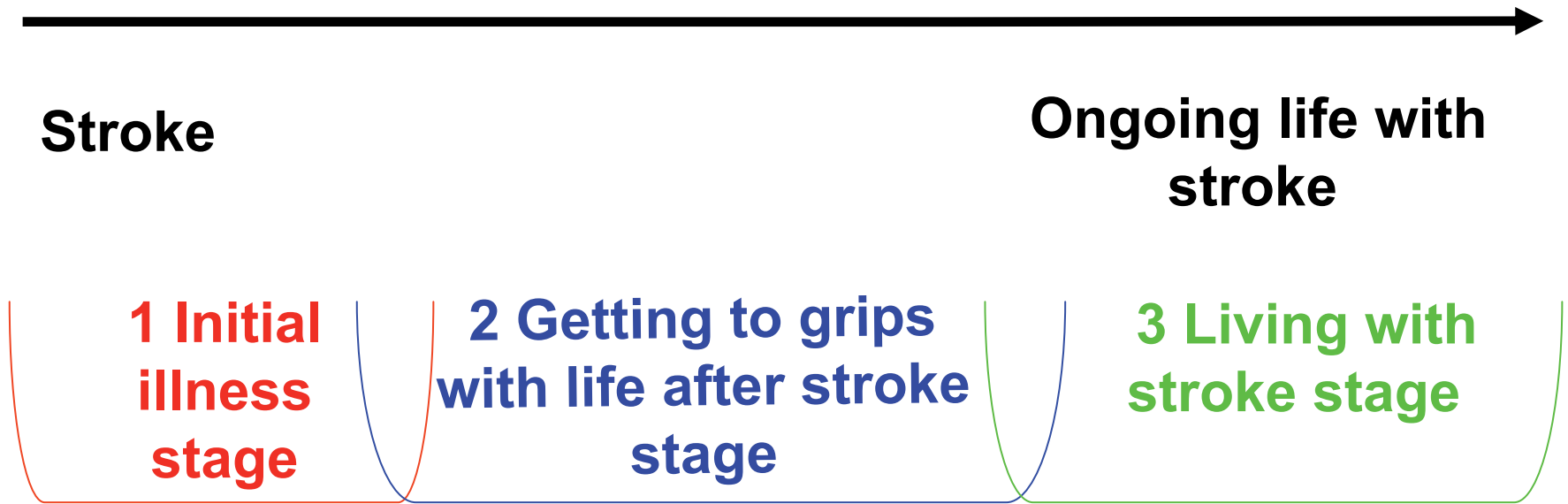
Getting back to life is a complex, long-term process:

- no one agency or organisation can meet all the needs
- it requires support from a range of sources
- it is not a smooth, linear process
- it requires more than just the provision of health and social care services

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# The timeline for providing support



# So do we have the right metaphor underpinning recovery?



...to a 'web' of support



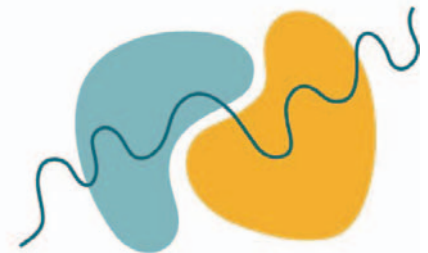
From a road to recovery ...

# What the web of support needs to offer

for people with stroke **and** their carers

- 'Grounding'
- Information and navigation
- Support for getting control of function & health
- Support for getting control over life
- Access to meaningful occupation
- Access to networks of support
- Awareness of stroke & its impacts

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# Elements of a comprehensive web of support

**Stage 1**  
**Initial illness stage**

**Stage 2**  
**Getting to grips with  
life after stroke  
stage**

**Stage 3**  
**Living with stroke  
stage**

## **Grounding**

**Information and navigation**

**Getting control of function & health**

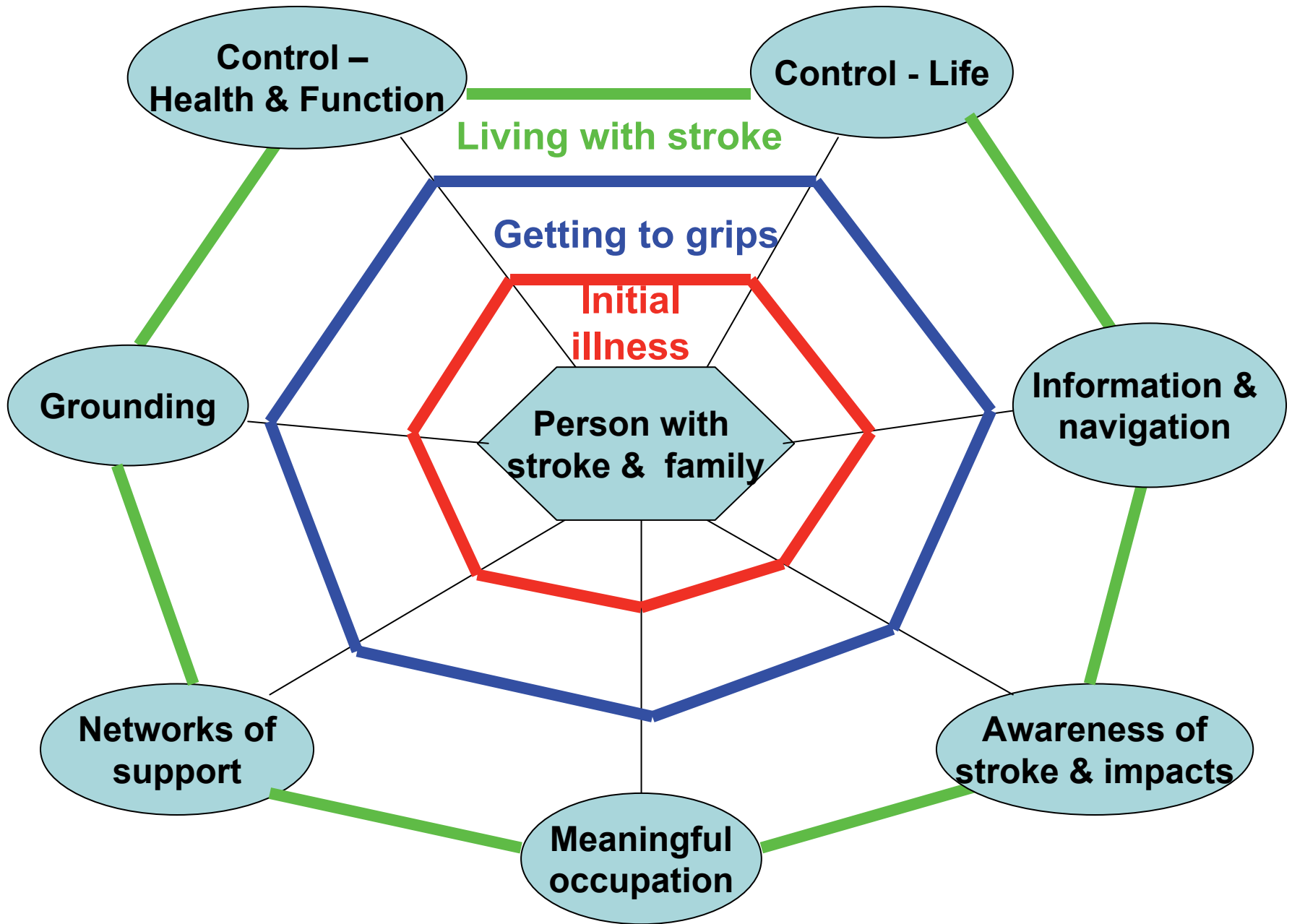
**Getting control over life**

**Access to worthwhile occupation**

**Access to networks of support**

**Awareness of stroke, its impacts, and prevention**

**- for people with stroke and their carers**



# The web of support

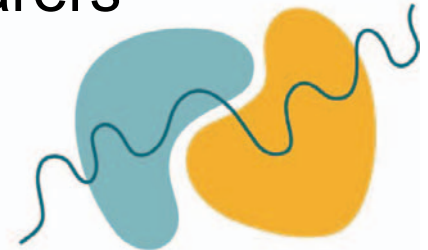
# 1 'Grounding'

## 'Grounding' – understanding stroke and its impacts:

- learning about and understanding **what has gone wrong** with e.g. movement, communication and language, swallowing, vision, memory
- over time, understanding what this **means in my life & my culture**

for both people with stroke and their carers

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# 1 'Grounding'

– support people want in practice

## Early on – in the initial illness stage

e.g.

- **accessible explanations** of stroke and its impacts by my bed without us having to ask
- **regular sessions with therapists, nurses & doctors** explaining my impairments to me and my relatives, helping us understand what this means
- **a trained person/relative with stroke** visiting me on the ward to help explain what it is

## Later – the getting to grips with stroke stage

e.g.

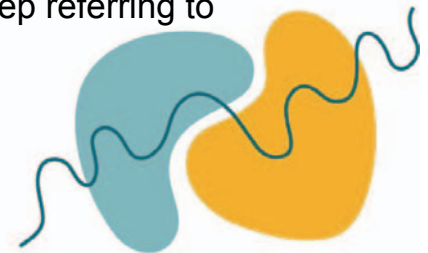
- **accessible explanations** of stroke and my impairments remain available
- **therapy, nursing sessions** continuing to explain my impairments with me and my family/carers
- **groups led by experts with stroke**, to learn how other people manage the impact of stroke
- **groups led by 'expert relatives'**, to share their understanding of stroke and its impacts

## Even later on – the living long-term with stroke stage

e.g.

- **ongoing access to opportunities to discuss stroke and its impacts** - to keep referring to when we need to refresh our knowledge and understanding
- **access to a community of peers** - where stroke and its impacts are taken for granted and not an issue – especially for people living with aphasia

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# 2 Navigation and information

Ongoing provision of information, and support for negotiation with service provider agencies, as life and circumstances change:

**1 Services and advice I might need:**

- where from?
- how can I get them?
- how long can I get them?

**2 Opportunities are available:**

- where from?
- how can I get them?
- how can I be supported to access them?

**3 Support for negotiations with providers – ‘brokering’:**

- ensuring goal planning is relevant to my life
- enabling me to be authentically part of decision making process
- helping me to negotiate the service options and choices available to me

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# 2 Navigation and information

– support people want in practice

## Early on: *in the initial illness stage*

e.g.

- comprehensive set of accessible information about the local stroke / long term conditions 'care system', made available immediately to me/us
- a **skilled 'navigator'** is available to me/us immediately, easily contactable, reliable and consistent, who knows the systems and can tell me/us what to expect to happen (this could potentially be a trained person with personal experience of stroke?)
- the 'navigator', who has good negotiation skills, meets with me/us, comes to goal planning sessions if I/we ask them to, and helps to 'broker' between me/us and a wide range of service providers

## Later& Even Later: *in the 'getting to grips & living with' stages*

e.g.

- the 'navigator' remains accessible to me/us when needed for information and brokering
- accessible, updated, local and nationally relevant information remains available, through a variety of means, e.g. workshops in primary care, printed, web-based

# 3 Getting control of function & health

Learning how to manage impairments

(e.g. movement, mobility, vision, perception, communication, swallowing, memory, attention, continence)

and maintain health:

- relearning
- developing techniques & strategies
- practice
- getting used to it being different
- maintaining health
- managing medication

for both people with stroke and relatives



# 4 Getting control over life

## Making sense of events:

### Feeling **confident**

- Feeling that there is **some order** and **sequence of events**
- Feeling that life is **going** somewhere, has a direction

### Knowing that **help** is **available**

- **where** to get it from
- **how** to get it

For people with stroke and relatives





# 3&4 Getting control of function, health & life

**Ideas for interventions:** For people with stroke and relatives e.g.

- Person-centred goal setting
- 1 to 1 therapies & exercises
- Group learning opportunities – in everyday contexts e.g. leisure centres
- Peer-led maintenance groups – e.g. conversation groups
- Adult education classes – literacy, numeracy, specific skills
- ‘Buddying’ to give confidence to take up opportunities
- Access to peer support for role models, ideas and inspiration
- ‘Taking Control’, self-management groups
- One-off workshops e.g. confidence building, information updates, experience sharing about access to social support systems
- Regular health checks to continue controlling the risk factors for stroke
- Clear, consistent information about the system to access aids and adaptations
- Refresher ‘self-care’ courses to keep up to date with how to maintain health after stroke
- Review appointments to acknowledge progress and problem solve new challenges
- Access to *planned* respite care

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# 5 Access to meaningful occupation

## Doing something meaningful:

- **Inspiration and encouragement** from other people with stroke that I can do something
- Ideas for **activities** to get engaged in that are **meaningful** to me
- **Opportunities** that are accessible

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Gill Marmor

id  
writing  
art class  
Theatre

# 5 Access to meaningful occupation

## Ideas for interventions

- Volunteering opportunities
- Return to work programmes
- Accessible leisure opportunities
- Accessible further education
- People with stroke as advisors, trainers, group leaders, peer supporters
- Involvement in research

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# 6 Access to networks of support

**A network of people who motivate, inspire and encourage:**

- **Access to people** who have been through what I am going through, who can inspire, motivate and encourage me
- **Access to family and friends** who can maintain contact, support me and help me think through what I want and how to achieve it
- **Access to health and social care providers** over the long term who understand my situation and know how to advise me
- **Access to local community groups and organisations** who provide opportunities and services relevant to me

For people with aphasia and relatives

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# 6 Access to networks of support

## – support people want in practice

### Early on – *in the initial illness stage*

*e.g.*

- a **trained person with stroke/relative** to visit me/my relatives in hospital / at home to keep me company & empathise with me

### Later – *the getting to grips with stroke stage*

*e.g.*

- **access** to a group of people with stroke, for support in trying out new activities – going to a café, using the bus, going to a concert
- access to **accessible counselling**
- a peer group of people with stroke coming to my care home to provide support & interest

### Even later on – *the living with stroke stage*

*e.g.*

- a buddy to support me, for instance in trying out a course at a local further education college, or getting to the library
- a virtual 'circle of support' through the Internet
- access to a group of people with stroke who are part of a supported national network – giving me a sense of belonging to a recognised community

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# 7 Awareness of stroke and its impacts

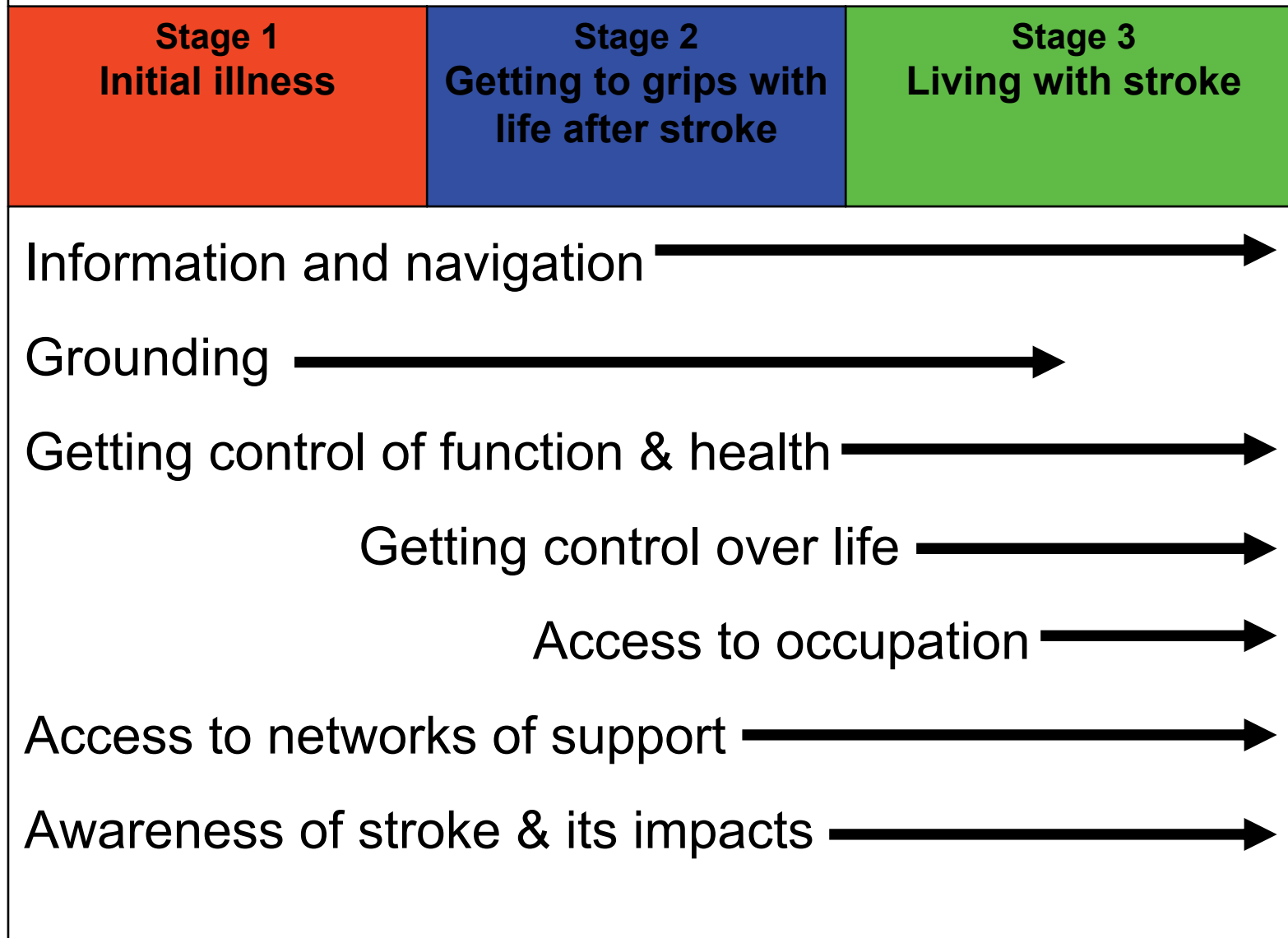
Partners, relatives, friends, colleagues, health and social care providers, public service providers, shopkeepers, transport workers, etc. etc.

- know what stroke is
- understand its impacts
- know how to modify their actions accordingly

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## Relative timings of the elements of the web of support across the timeline of stroke



# Key providers of services & opportunities across the timeline

## Acute Care Settings:

Main provider - NHS

Supported by – Voluntary Sector

## Community settings:

### Main providers:

- Social Care agencies
- NHS
- Specialist Voluntary Sector

### Supported by –

- Other voluntary sector agencies & community organisations

## Community Settings:

Main providers – a range of voluntary, community, & public sector agencies, as well as people living with stroke

Supported by – Specialist services – vol sector, NHS

Stroke

Ongoing life with stroke

1 Initial illness stage

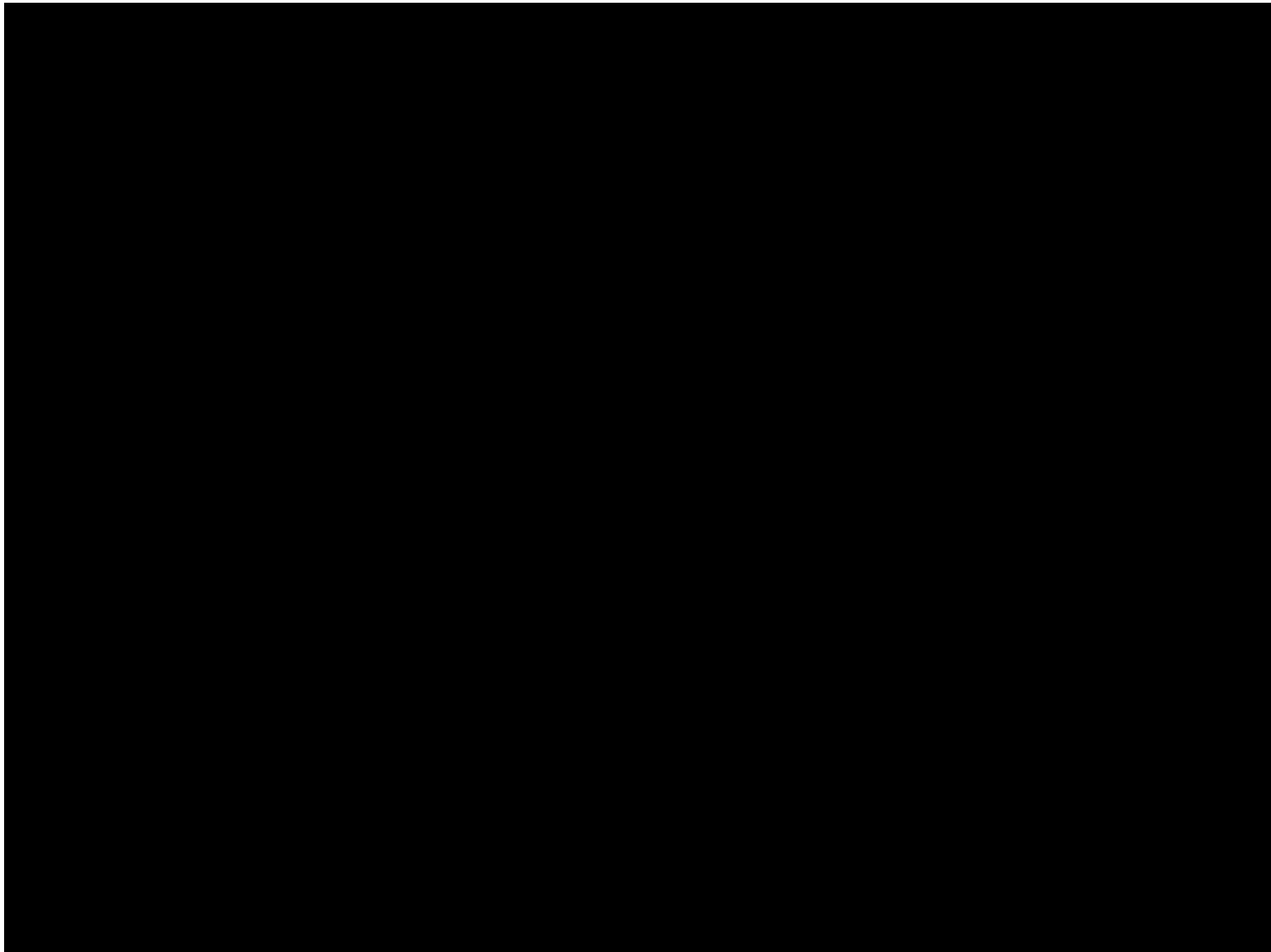
2 Getting to grips with life after stroke stage

3 Living with stroke stage

# An illustration

## Debbie's story





# Debbie's story

- Achieving meaningful occupation
- Creating a network of support
- Providing ongoing opportunities for
  - grounding
  - getting control over life
  - control of function & skills building
- 'Light touch' support, not involving expensive services or systems

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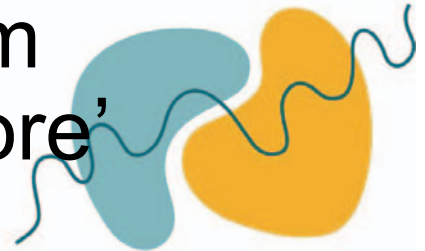


# Key messages

Getting back to life after stroke requires

- a rich and creative 'pick and mix' of accessible services and opportunities
- good information, signposting and navigation
- does not have to involve only expensive systems and people
- experience and creative input from people who have 'been there before'

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