



# “This is our life now. Our new normal”: A qualitative study of the unmet needs of carers of stroke survivors

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In partnership with our community



**Health**  
Hunter New England  
Local Health District

# Who are informal carers?

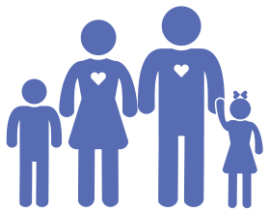


Around 50% of people who have a stroke will require support from a carer



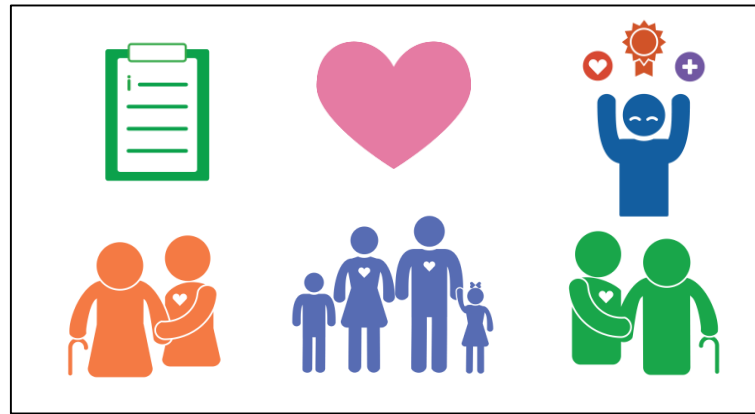
**Informal carers =**

Spouses, family members, friends



Provide support to someone who has had a stroke





Low

High

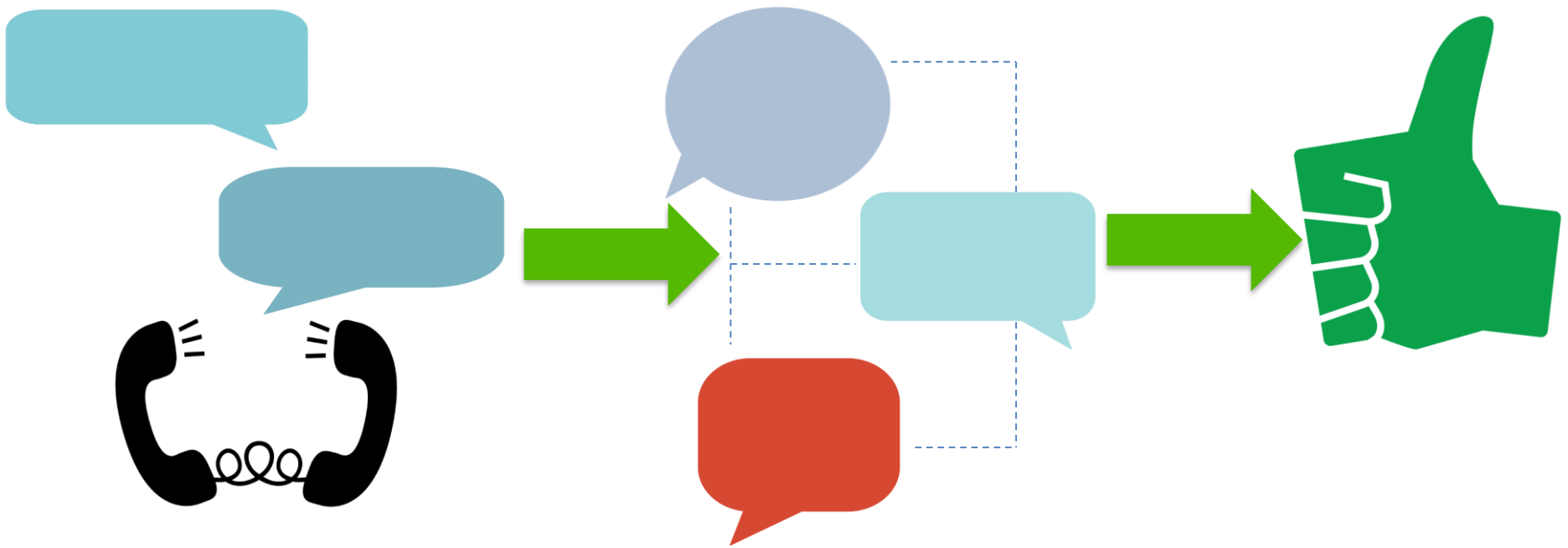
Continuum of care provided  
by informal carers

# Unmet needs of carers of stroke survivors

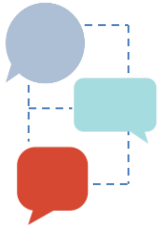
Unmet needs refer to a need that is not satisfied through available and accessible services



# Co-design



# Aims



To qualitatively explore the unmet needs of carers of stroke survivors



Their preferences for interventions and support services

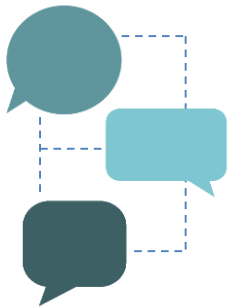
# Method



Community Stroke Service and the Hunter Stroke Research Volunteer Register



Semi-structured phone interviews



Inductive thematic analysis

# Results (n=24)

## Female

19 females (79.2%)

## Spouses

16 Spouses (66.7%)

4 Adult children (16.7%)

3 Parents (12.5%)

1 Aunt (4.2%)

## Working age (M=56.83)

Between 30 – 87 years





# Themes of unmet needs

- Social relationships and support
- Adequacy of information
- Taking care of oneself
- Accessing appropriate services

# Social relationships and support

**“My wife’s family ...dropped off the Earth. We haven’t seen them since the stroke and I mean that was hard, that was part of [my wife’s] depression.”**

**“Other people that get what you're going through, not just can sympathise or empathise ... But really get it because they’re living it too.”**

# Adequacy of information

“I didn’t know what to expect and I wasn’t given any directions or any assistance or anything you know. So initially it was just frightening.”

I was given a pack from the hospital and that’s it—I had to take it home and read.  
I was terrified.  
There was just no-one for me to talk to.”

# Taking care of oneself

**“I focused on my work, my family and my husband to the physical detriment of myself.”**

**“I’m so stressed out my ulcerative colitis has flared up, I’m doubled over in pain most of the day at work. I just never get a break. I’m just miserable to be honest.”**

# Accessing appropriate services

At first the NDIS provided lovely care.

Every week day, and a couple of hours on the weekend. On a Saturday. But this year the support has just disappeared.”

“I keep asking what will happen when he comes home?

What services will be in place for him and I?

And what I’m quickly discovering is that they’ll wait for a disaster and then they’ll deal with that.”

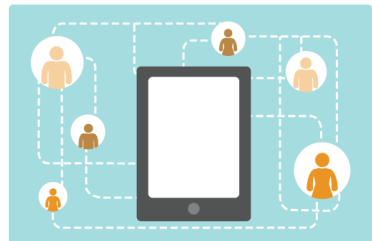
# Preferences for services



Connecting carers to a single service that provides ongoing support



Community and social activities with other carers



Face-to-face and online

# Conclusions



Carers described how their relationships were impacted post-stroke



Carers also experienced a decline in their mental and physical health as a result of providing care



Difficulties in accessing much needed support

# Conclusions



Ongoing supportive services may improve carers' health and wellbeing outcomes



This research informs the develop of co-designed resources to support and meet their needs



# Thank you!

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