embedding carers outcomes; from research to policy and practice (and back again)

Emma Miller

…sometimes the river is too wide to cross and sometimes you need a lily pad to get you over…

Young person, Talking Hope project

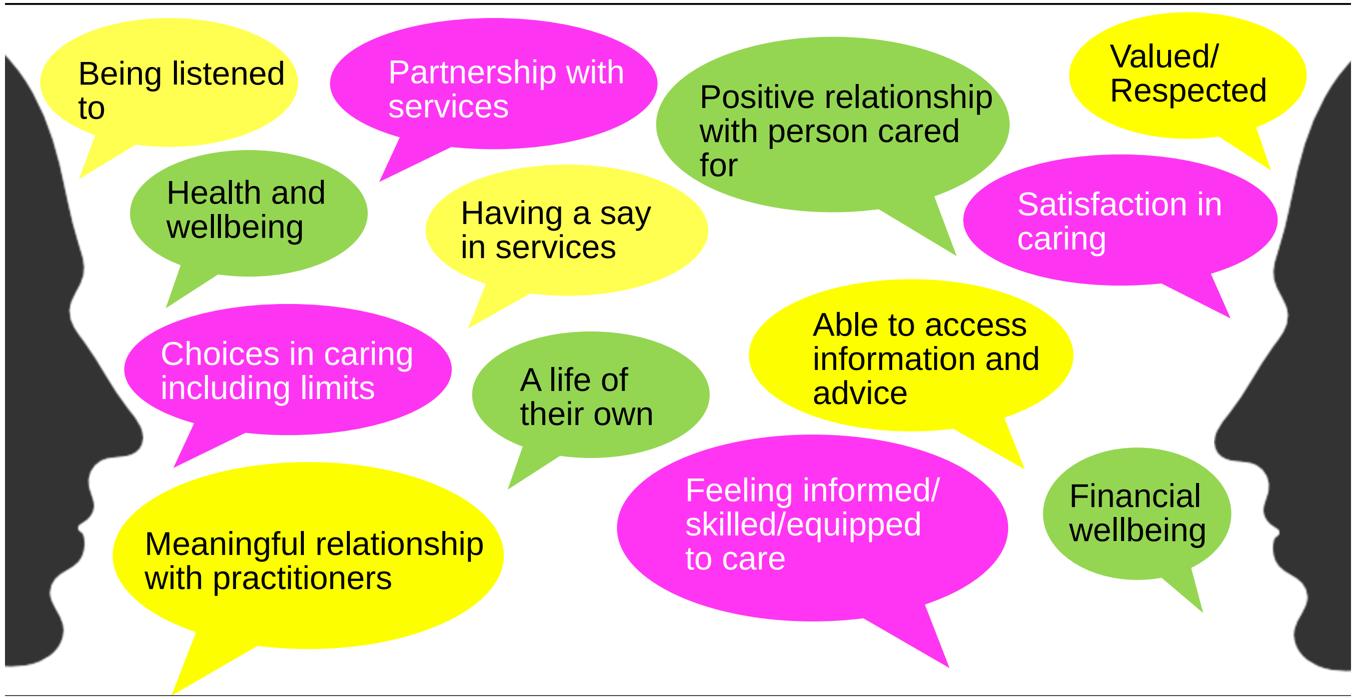
Review of evidence on outcomes for carers

- Long term programmes of work on outcomes focused planning for carers in England, Canada, Sweden, Wales, and Scotland
- In England the Social Policy Research Unit (SPRU) at York University more recently the Personal Social Services Research Unit (PSSRU)
- In Wales by Diane Seddon and colleagues
- In Sweden by Elizabeth Hanson and colleagues
- In Canada by Nancy Guberman and colleagues
- In Scotland initially by the Joint Improvement Team

Review of evidence on outcomes for carers

- Social Policy Research Unit work from 1996
- Similar sets of outcomes for people using services and carers – includes both quality of life and process outcomes
- Carers also managing the caring role and QoL for cared for person
- Move from identifying deficits and matching them to services to engaging with the person in the context of their whole life
- Focuses attention on the intended impact, or purpose of support
- Exchange model of assessment – move from Q and A to conversation

Outcomes for carers



Being listened to

Partnership with services

Positive relationship with person cared for

Valued/ Respected

Health and wellbeing

Having a say in services

Satisfaction in caring

Choices in caring including limits

A life of their own

Able to access information and advice

Meaningful relationship with practitioners

Feeling informed/ skilled/equipped to care

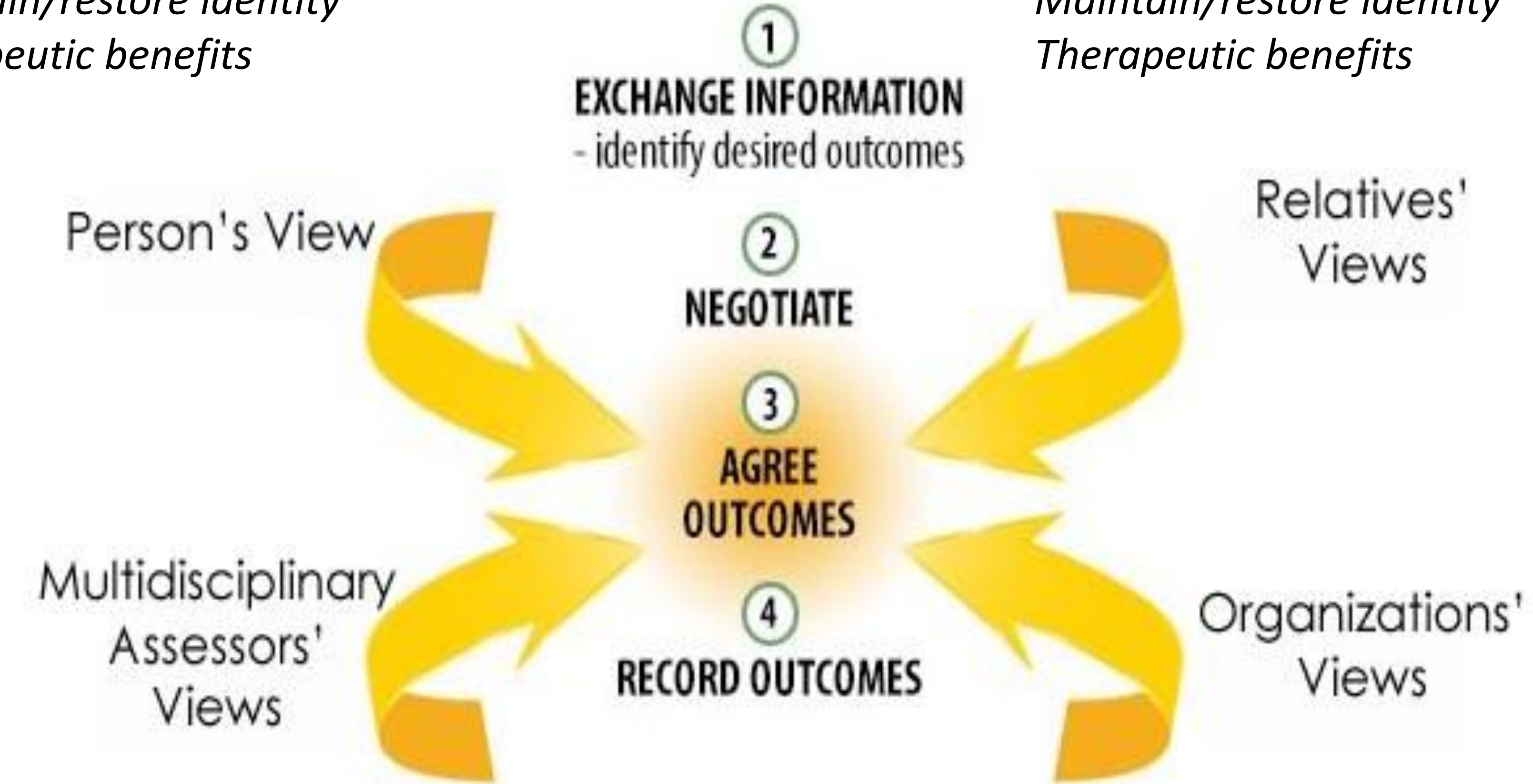
Financial wellbeing

• managing the caring role. • their own wellbeing and having a life alongside caring • being treated as a partner by services • quality of life of the person they care for

Exchange model of Assessment (originally Smale et al)

Listened to
Build on strengths
Maintain/restore identity
Therapeutic benefits

Listened to
Role acknowledged and valued
Maintain/restore identity
Therapeutic benefits



Role validation
From fixer to facilitator
Shared purpose (with person and family too)

Better outcomes for everyone
More effective use of resources
Shared responsibility

Recording Personal Outcomes ~ What to Look for

- Distinction between outcomes and outputs
- The outcome is personalised
- The person/family has a role
- Uses person’s own language as appropriate
- Action oriented (usually)

Source: Miller and Barrie (2015) Recording outcomes in support planning and review

Carers outcomes

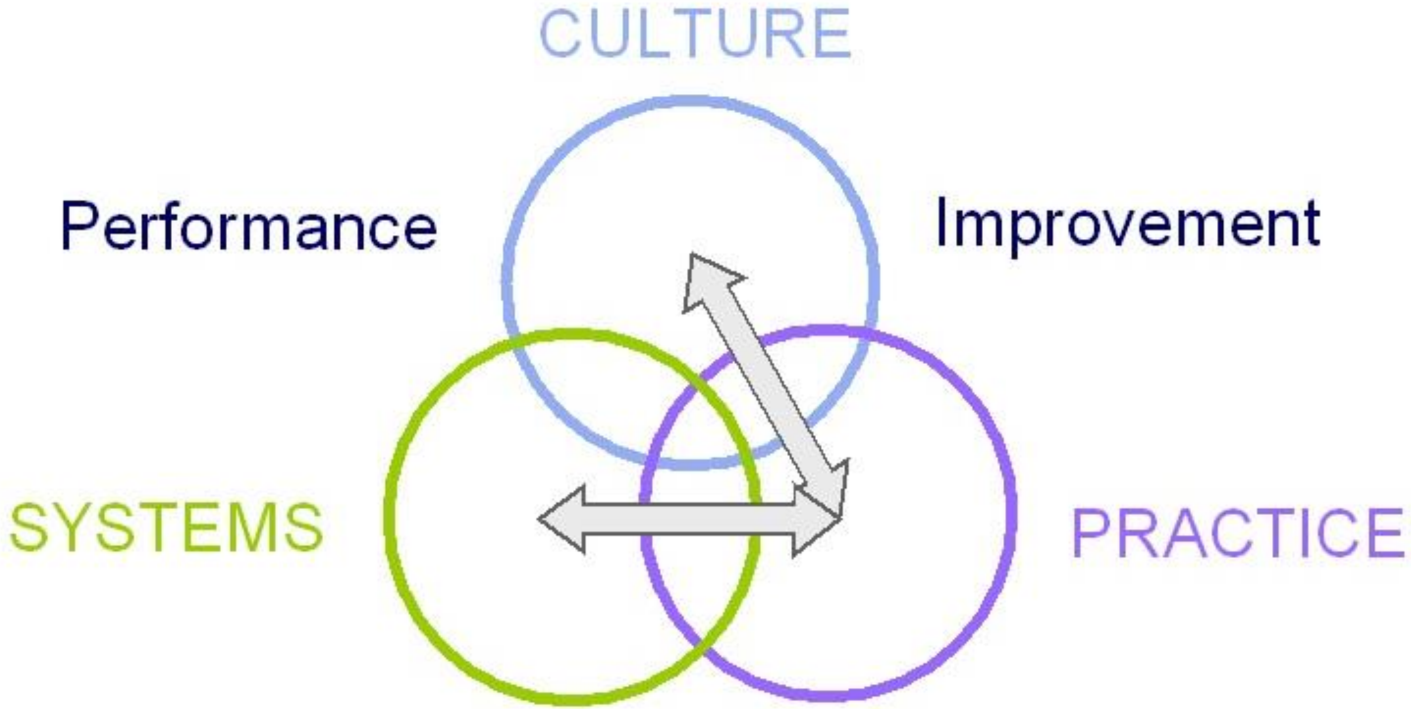
- *To feel less anxious so I don't wake up so often at night*
- *To be able to hang out with my pals at the weekend*
- *To meet and connect with other carers of adults with early onset dementia*
- *To have the energy and some headspace to start painting again*
- *To have support to have my husband stay at home with me as long as possible*
- *To feel confident that my father has carers he knows so he doesn't get anxious and I get called home from work*

Meaning and measurement

Contribution not attribution

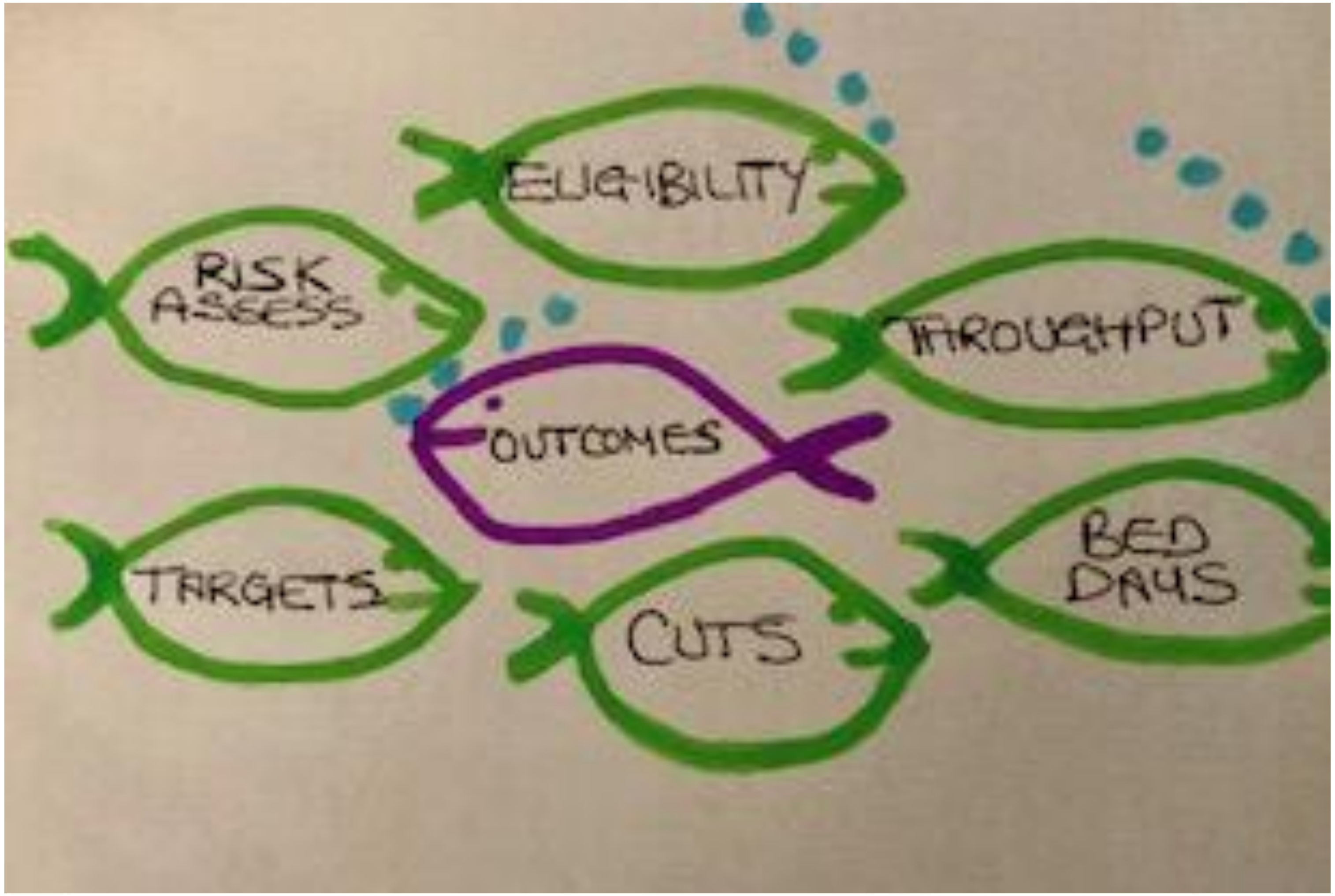
Regarding measurement, there is a view that tracking outcomes is a helpful concept in allowing for inclusion of narrative data, and fluctuations over time

The MM project called into question the implicit measurement assumption that a ‘higher score’ is necessarily better and that all aspects of wellbeing should improve



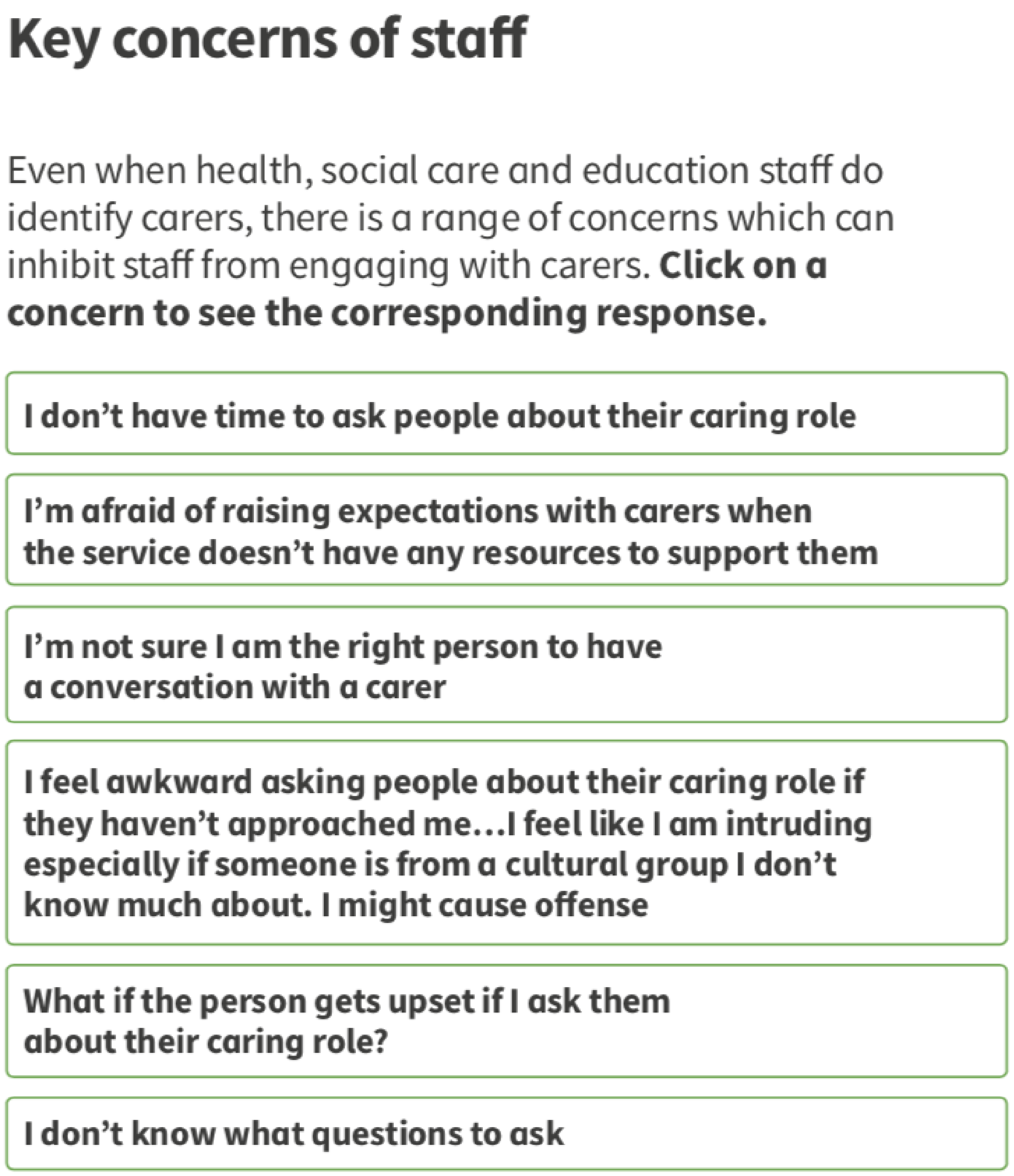
An organisational approach

- Supervision and support to staff
- Modelling an outcomes approach
  - Facilitating not fixing
  - Recognising strengths
  - Listening



In certain conditions, culture and systems influence practice in unhelpful ways too. The lilypad is lost

Equal Partners in Care - EPiC



Key concerns of staff

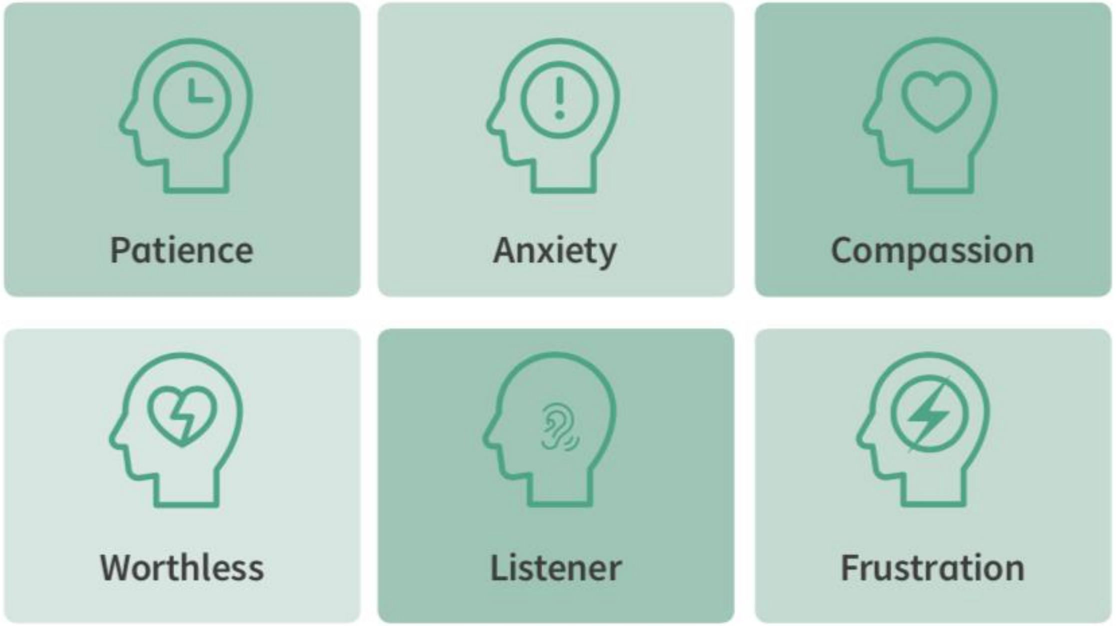
Even when health, social care and education staff do identify carers, there is a range of concerns which can inhibit staff from engaging with carers. **Click on a concern to see the corresponding response.**

- **I don't have time to ask people about their caring role**
- **I'm afraid of raising expectations with carers when the service doesn't have any resources to support them**
- **I'm not sure I am the right person to have a conversation with a carer**
- **I feel awkward asking people about their caring role if they haven't approached me…I feel like I am intruding especially if someone is from a cultural group I don't know much about. I might cause offense**
- **What if the person gets upset if I ask them about their caring role?**
- **I don't know what questions to ask**

Understanding that carers sometimes minimise challenges… the ‘I’m fine’ conundrum

Lanarkshire Carers Centre have adapted a resource called Emotional Touchpoints to help to change the conversations they have with carers. Staff and carers worked together to develop and test a set of additional prompt cards. The cards are used to support conversations about the effect the caring role is having on the carer.

> *Before thinking about the plan, I try and find out ‘how are you feeling?’ and ‘what effect is caring having on you?’ Some people are very good at putting on a front and will insist everything is fine. And using normal questions, that can put people’s defences up – you can actually see people withdrawing away from the conversation. We adapted emotional touchpoints and I thought what about using some prompt cards that have just words on them. And allow carers to take their time and choose the cards that most reflect how their caring role affects them.*
>
> **Support Worker,**
> Lanarkshire Carers Centre



Patience

Anxiety

Compassion

Worthless

Listener

Frustration

The boxes above are sample word cards from many used by the carers centre to encourage carers to explore their feelings about the role. When staff and carers developed the resource they deliberately put in positives to support people to identify their skills and strengths.

Professionals who are also carers: Kevin's story

Kevin is a nurse whose partner Ella was diagnosed with terminal cancer and only lived a few months longer. They had a daughter Carrie who was 12 at the time.

There are contradictory effects of being a caring professional in a family caring situation. Although as professionals we might have useful knowledge that can help us in our caring roles we need to accept that a caring background does not make us immune to needing help and advice as a family carer. Because we have experience of working in the system I think we also see things differently at times. It throws it all into sharp focus. You can get agitated because you have expectations of how things should happen but you also hugely appreciate it when you get that human connection.

References

- Miller, E. and Barrie, K. (2019) Narrative recording as relational practice in social services: a case study from a Scottish carer support organisation, *British Journal of Social Work* https://doi.org/10.1093/bjsw/bcz100
- Miller, E. (2017*) Review of research evidence on personal outcomes relevant to the Carers (Scotland) Act 2016*, advisory report commissioned by the Carers Branch of the Scottish Government
- McBride, T., Miller E., and Dewar, B. (2017) "*I know who I am; the real me, and that will come back:*" The importance of relational practice in improving outcomes for carers of people with dementia, *Illness, Crisis and Loss,* online version
- Miller, E. (2012) *Individual outcomes: Getting Back to What Matters* Edinburgh, Dunedin

Resources

- **Personal outcomes collaboration website**
- http://personaloutcomescollaboration.org/

- **Personal outcomes network**
- **Contact** e.miller@strath.ac.uk
- **Twitter** @personaloutcom1