

**The magic of the ordinary:**

**Shared Decision Making, resilience  
and empowerment**

# What do people do?

Succumb  
Survive  
Recover  
Thrive

Pressure of  
teleological time

A lack of  
information,  
clarity and  
support

Disruptions to  
treatment

Not being in contact  
with people that  
matter most

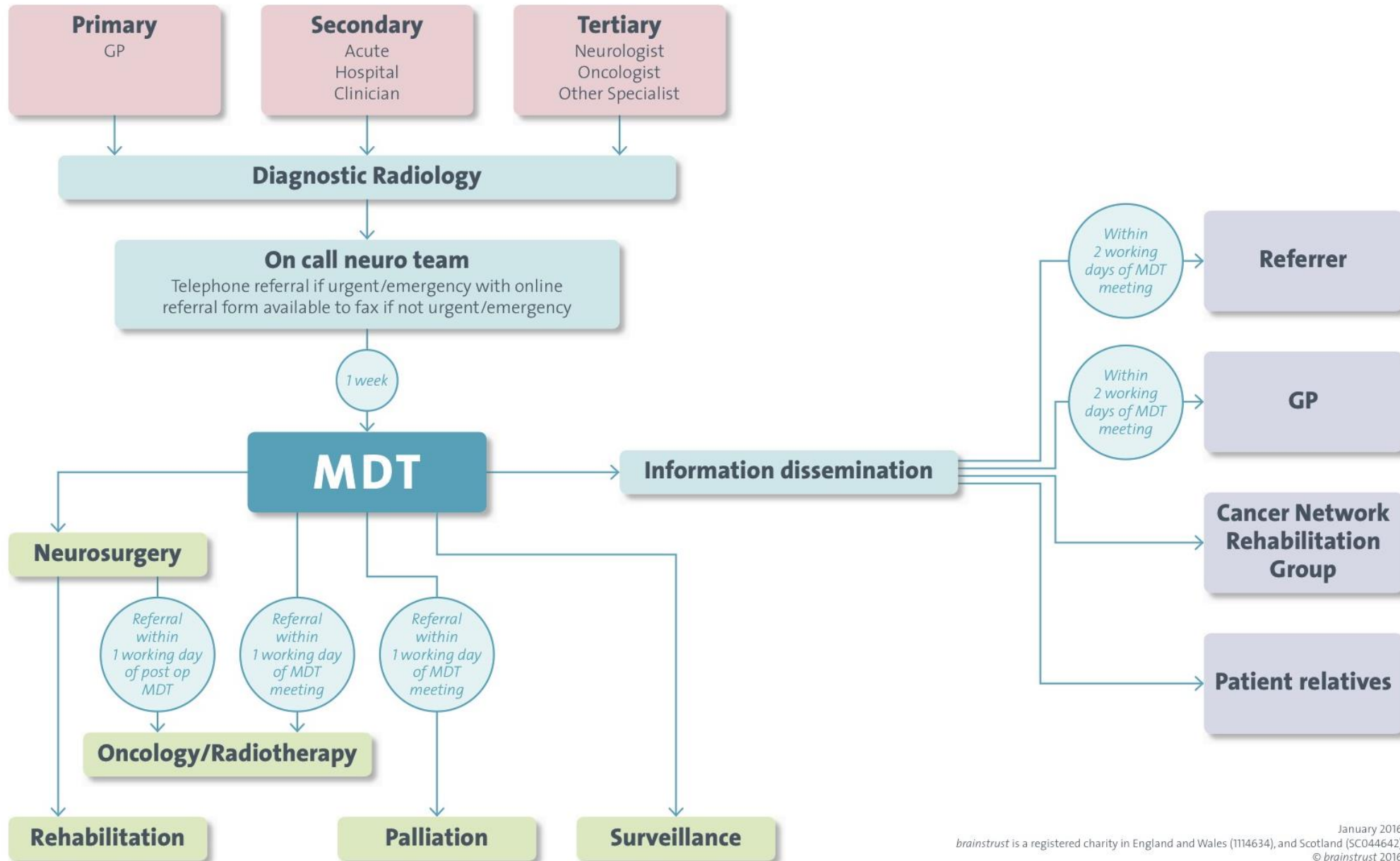
# Andrew

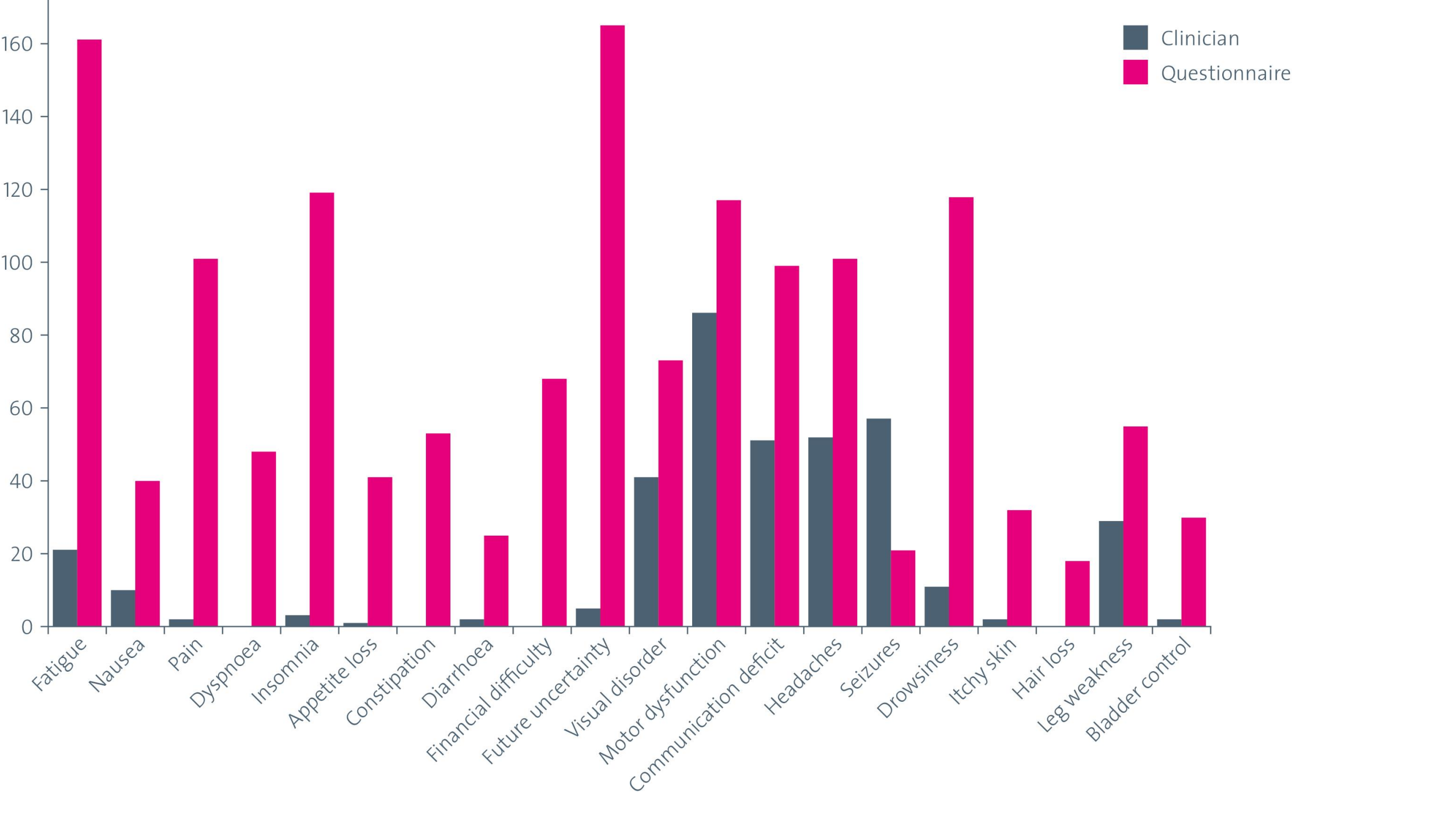
- 42 yrs, 3 teenage children, recently divorced, shared care of children, rented accommodation.
- GBM, lost driving license and job, cannot afford child maintenance, remote from family.
- Angry, fearful, sad, guilt, proud, anxious. Not sleeping, reduced functioning, isolated.

# Climate

- Shared decision making
- Google
- Autonomy
- Entitlement
- Hope v bleakness
- Disease trajectory
- Current model of care

# The patient's journey





# Non negotiables

- Maintenance of wellness, not treatment of illness
- Keeping the person at the heart
- Shared decision making
- Talk research
- Transition points
- Joy of local
- Built on current good practice
- Evolving models
- Robust infrastructure
- Prepared patients, trained teams and supportive systems

# The lived experience of the person who has thrived

# Colin

Diagnosed with a GBM 28 January 2023

56 years old

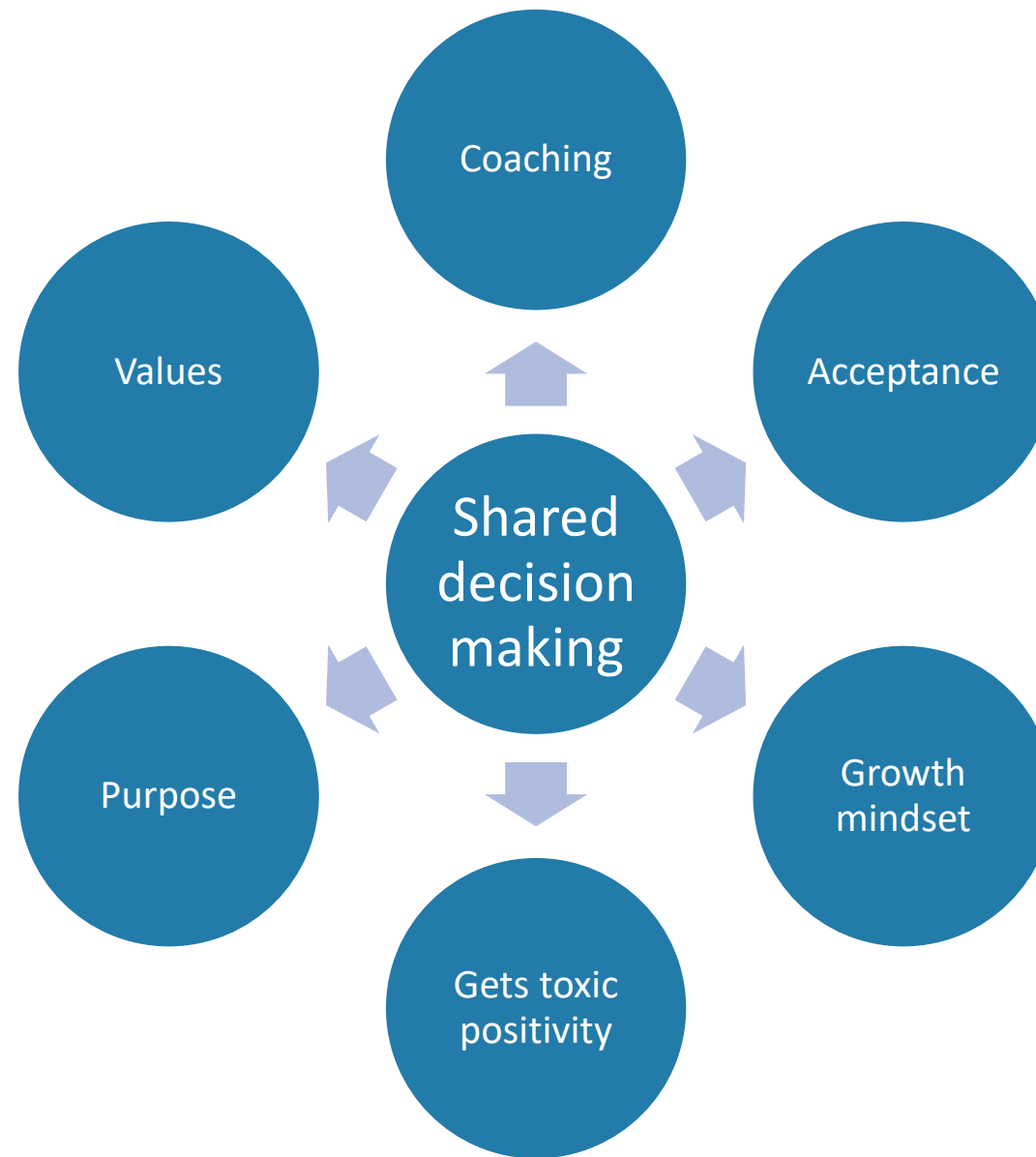
Married

3 daughters, 4 grandchildren

Standard protocol

Recurrence September 2023

# Colin's toolkit



# Shared decision making – the landscape

- What does the average patient need to know to be able to make an informed decision?
- What does this particular patient need to know and understand to be able to make an informed decision?
- How do we close this gap?

# The role of shared decision making

- the clinician's expertise, such as treatment options, evidence, risks and benefits
- what the patient knows best about their preferences, personal circumstances, goals, values and beliefs.

# The patient/carer led solution

Use of communication skills and coaching techniques - focus on the future and on development of a workable solution

Enables people to recognise and face their challenges and learn how to develop resilience and use resources to their full potential

Listen, listen some more... then ask some simple questions.

# Doing it well

Concrete information – the facts

*Ask ‘what do you know about your diagnosis?’*

The emotive responses - the feelings

*Ask ‘What are you struggling with?’*

The interpretation – deep grappling finds the meaning

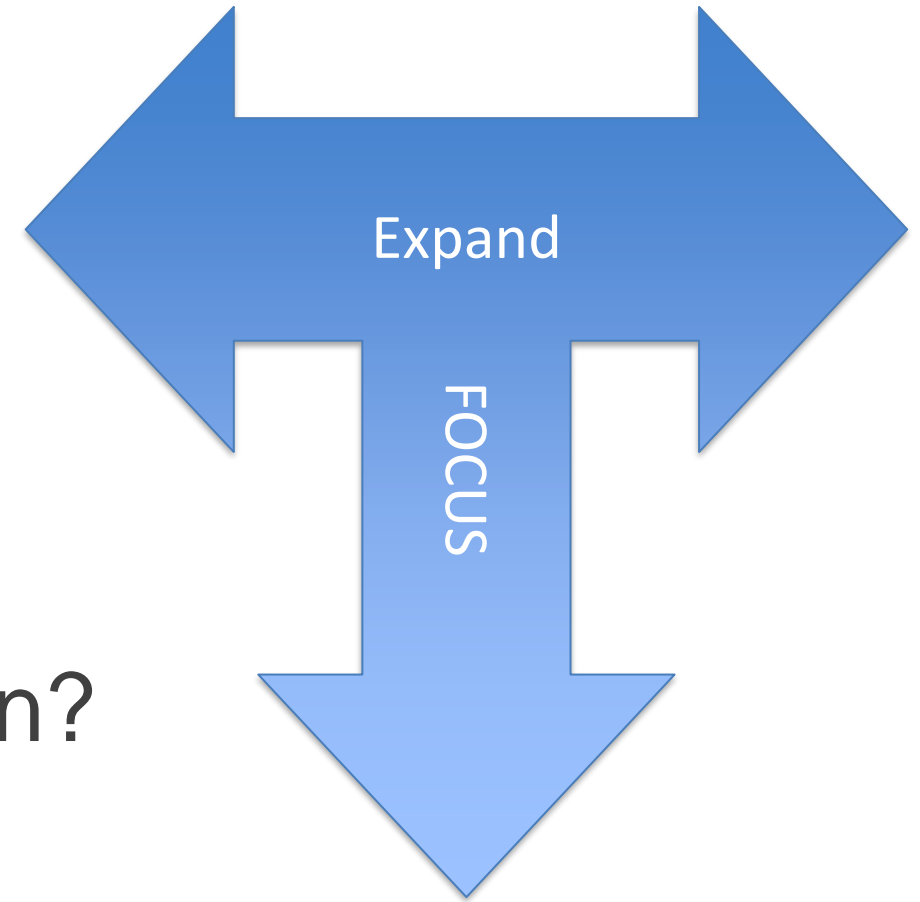
*Ask ‘What does this mean for you?’*

The decision – resolve closes the conversation

*Ask ‘What do you want to do?’*

# T - Grow

- T What is the **t**opic?
- G So what's the **g**oal?
- R What is the **r**eality?
- O What are the **o**ptions?
- W What **w**ill you do? By when?



# Good questions

- G** How would this be time well spent?
- G** What do you want to discuss?
- G** What would be a good goal for you?
- R** Right now, at this very moment, how are you?
- R** What are you struggling with? What else? What else?
- O** What's important to you?
- O** What are the risks and benefits for you?
- O** How do you want to be in the time you have left?
- O** What's important to get right?
- W** What support do you need?
- W** What are the next steps for you? Who can help you?

# Other tools


Summarising

Playback

Intuition

Headlining/bottom lining

Metaphors



Say what you  
notice.  
Not what you  
think.

# Conflict

- What relationship do I want to have?
- What unites us? What is our common purpose?
- Where do we think differently?
- What prejudices am I holding?
- How important is the issue in the grand scheme of things?
- What are my options?
- What's my bottom line?

# And our behaviour

Let the conversation happen

Give space to silence

Silence the chatter in your own head

Sit still, breathe slowly

Understand that this is just one conversation

Say what you sense

Acknowledge

Close

# Ask Andrew

- What does he need to be different?
- What does he want for people like him?
- What does a good result look like?
- What are the reasons to do something? And to not?
- Who can we work with?

**The only source of data is the patient**

**Thank you**

**[helen@brainstrust.org.uk](mailto:helen@brainstrust.org.uk)**