

The impact of a brain tumour and the need for psychosocial research

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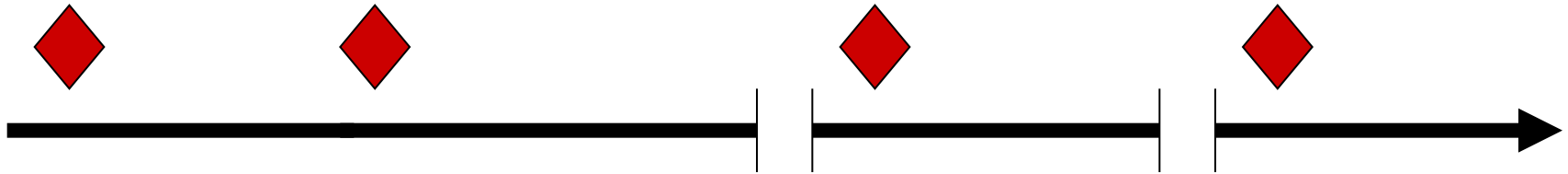
ST4 Psychiatry, South-east Scotland

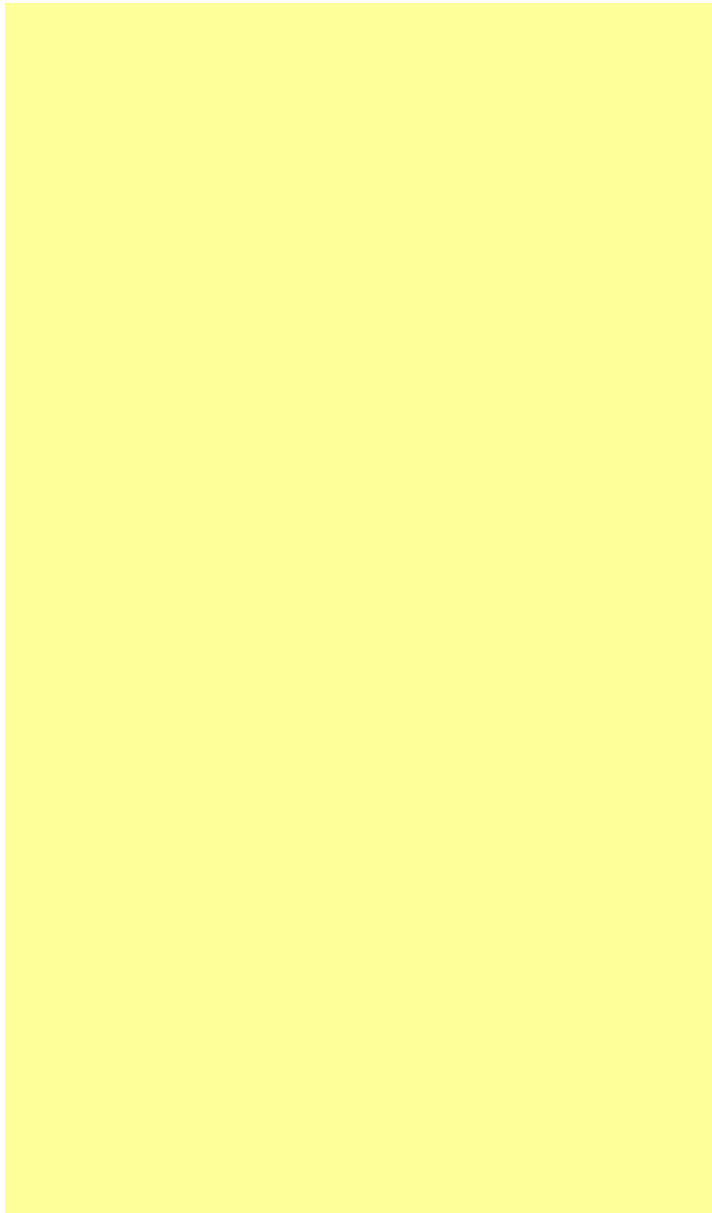
Diagnosis

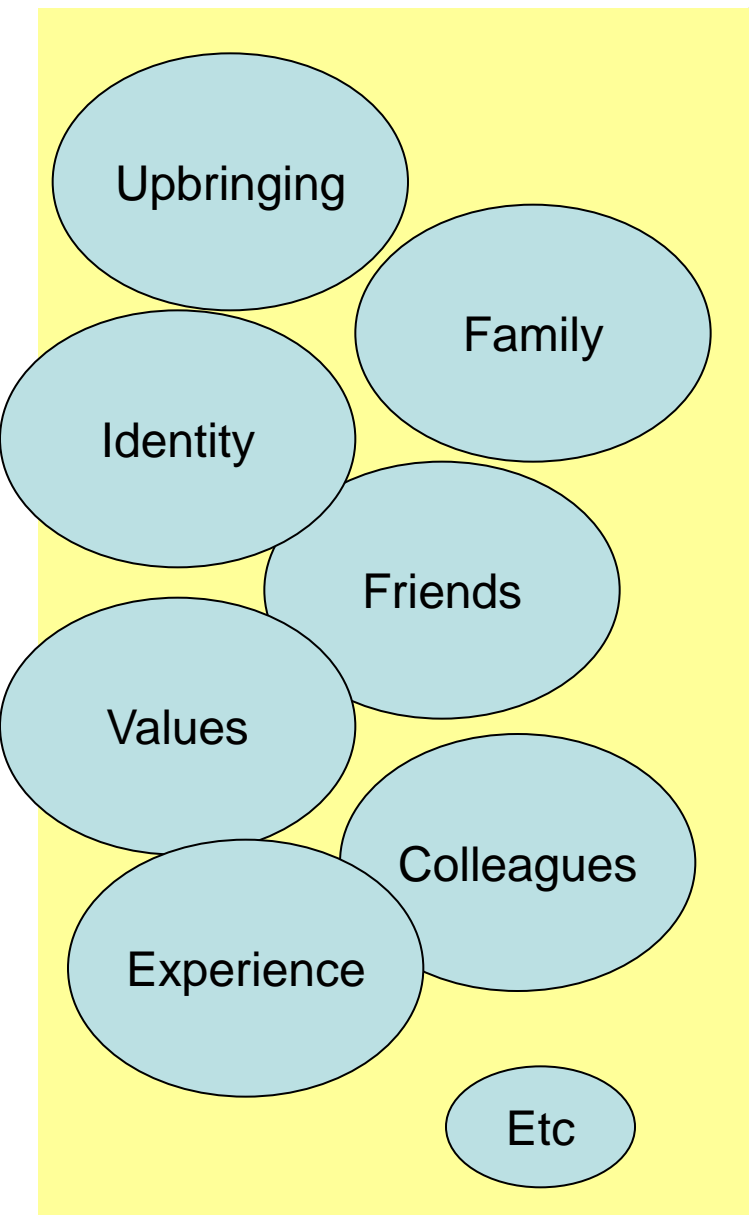
End 1' treatment

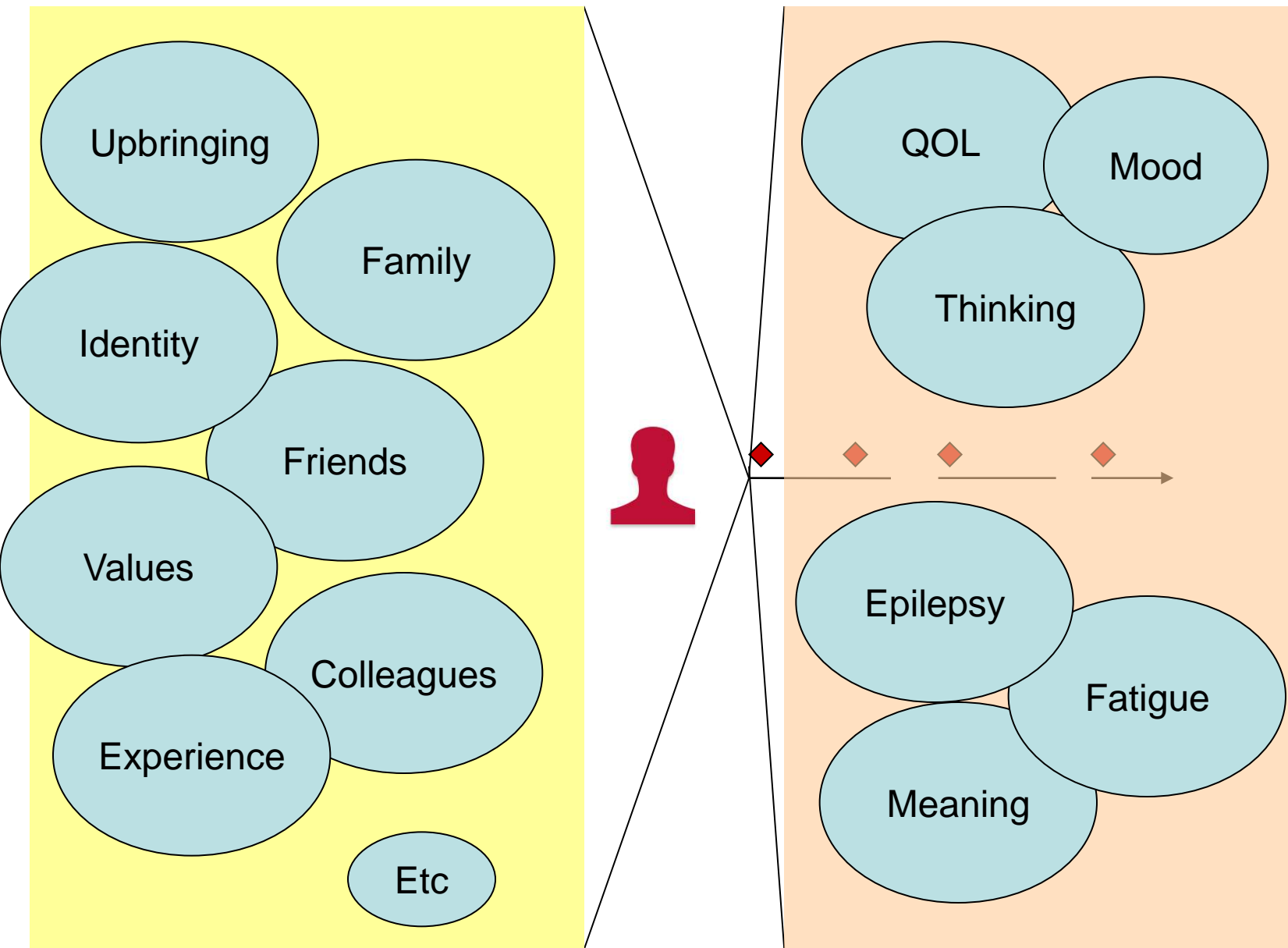
Recurrence

Palliation







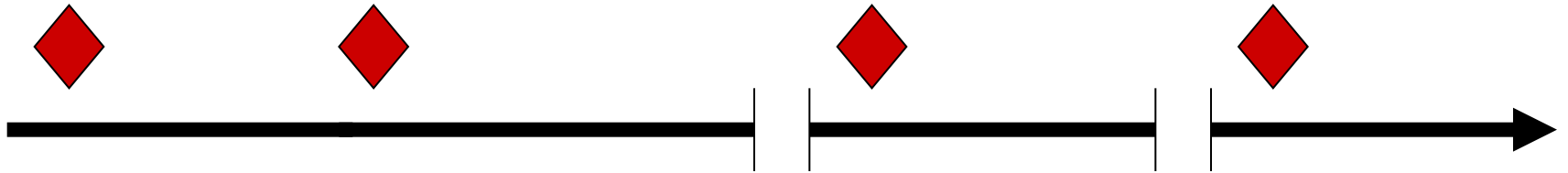


Diagnosis

End 1' treatment

Recurrence

Palliation

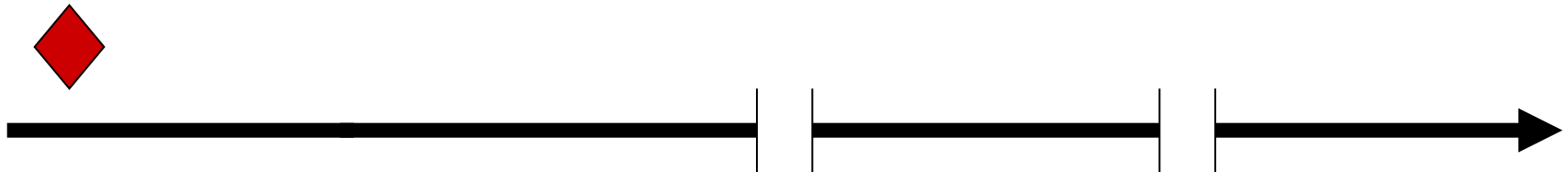


Diagnosis

End 1' treatment

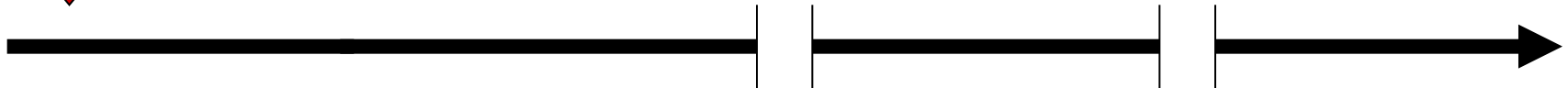
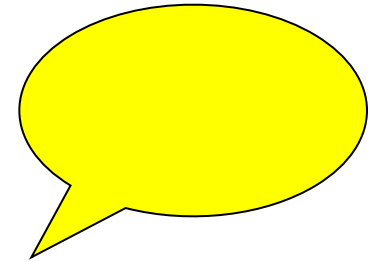


Diagnosis



Most patients understand that they have a brain tumour.
Only about half are aware of prognosis (relatives more).
Information about prognosis needs tailored to individuals.
Maintaining hope is vitally important.
The best way of delivering information is unclear.

Diagnosis



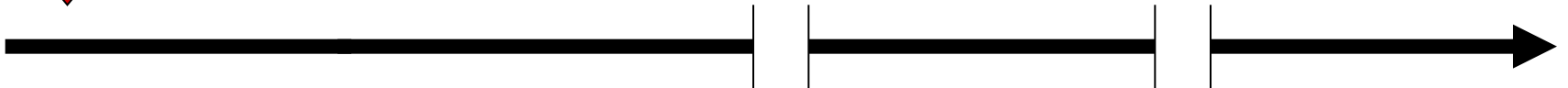
Quantitative research measures specific aspects of living.

-Severity or frequency of symptoms ; Quality of Life

Qualitative research reports the wider lived experience.

- Meaning ; understanding ; contextualising

Diagnosis



Some cognitive dysfunction is almost universal.

Psychiatric symptoms c.20% (mood / anxiety / personality).

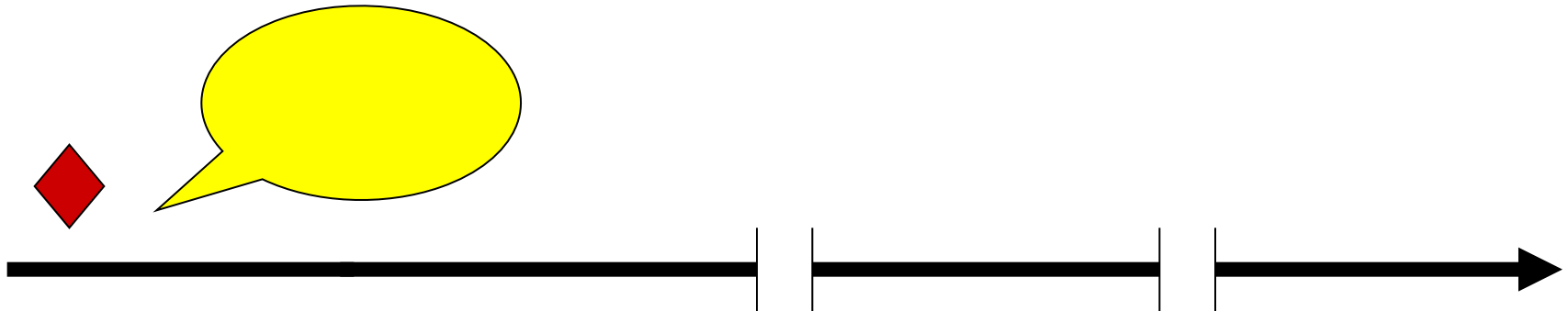
Fatigue c.60%.

Epilepsy – depends on tumour type (40 % – 80%).

Depression is common in glioma

| Study | Method | Depression (%) | Study | Method | Depression (%) |
|----------------------|------------------------------------|----------------|----------------------|-------------------------------------|----------------|
| Anderson 1999 | HADS (≥ 11) | 0 | Armstrong 2002 | MMPI-2 | 33 |
| Grant 1994 | | 21 | Litofsky 2004 | SF-36 (≤ 60) | 93 |
| Janda 2007 | | 17 | Litofsky 2004 | Three questions | 73 |
| Kilbride 2007 | | 10 | Edvardsson 2006 | Patient recall | 7 |
| Pringle 1999 | | 16 | Sherwood 2006 | NPI-Q depression | 60 |
| Kaplan 2000 | BDI (≥ 10) | 39 | Litofsky 2004 | Physician report | 15 |
| Mainio 2005a | | 42 | Anderson 1999 | HRDS (≥ 18) | 15 |
| Pelletier 2002 | BDI-II (≥ 14) | 38 | Gathinji 2009 | Outpatient notes | 5 |
| D'Angelo 2008 | ZSDS (≥ 50) | 10 | McGovern 2003 | Inpatient notes | 22 |
| Giovagnoli 1996 | | 8 | Rooney 2009 | GP records | 24 |
| Brown 1996 | POMS | 10 | Wellisch 2002 | SCID interview | 28 |
| Taphoorn 1992 | POMS | 43 | Siegel 2008 | Clinical interview | 6 |
| Arnold 2008 | PHQ-9 (≥ 6) | 41 | Davies 1996 | Clinical interview | 8 |

Diagnosis



Profound fear, anxiety, and distress.

Delays in diagnosis may lead to recrimination.

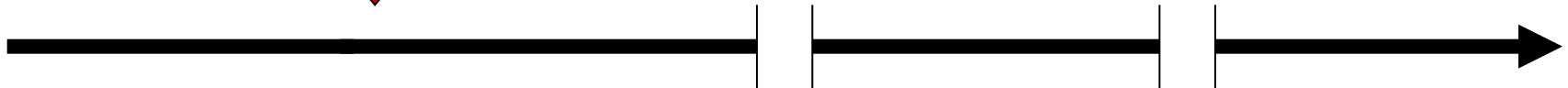
Patients and carers want to feel involved in decisions.

There is often a perceived lack of information.

Debbie Cavers' thesis (Edinburgh):

- Thoughts of recurrence, death and dying were prominent, especially once the initial surgery / diagnostic process was over.
- Hopes was often derived from patients feeling physically well, and changed over time.
- Patients often “read between the lines” of what the doctor said, rather than asking feared questions.
- There were wide differences in approaches to coping with glioma.

End 1' treatment



Most research occurs during / after primary treatment.
Clinical depression: 10-15%; other psych unclear.
QoL affected by mood, fatigue, cognitive impairment...
Fatigue c.60%, higher c.6 weeks after radiotherapy
Epilepsy often better controlled by medication.

EDINBURGH NEURO-ONCOLOGY PATIENT CONCERNS INVENTORY

1 Please tick any issues that have been a concern for you recently:

PRACTICAL

- Child care
- Financial benefits
- Holidays
- Housing
- Insurance
- Recreation
- Transport or driving

FAMILY

- Dealing with children
- Dealing with partner
- Ensuring support for family

EMOTIONAL

- Anger or irritability
- Fear of tumour coming back
- Other fear, anxiety or worry
- Personality changes
- Sadness, low mood or depression

SPIRITUAL

- Difficulty relating to God
- Loss of faith
- Loss of meaning to life

PHYSICAL

- Appearance
- Appetite or eating
- Bathing or dressing
- Breathing
- Changes in urination
- Concentration
- Constipation
- Co-ordination
- Diarrhoea
- Epilepsy, or seizures
- Fatigue, tiredness or low energy
- Feeling swollen
- Fever
- Headache
- Indigestion
- Memory
- Metallic taste in mouth
- Mobility/getting around
- Mouth sores
- Nausea or vomiting
- Nose dry/congested
- Pain (apart from headache)
- Sex or intimacy
- Skin dry, or itchy
- Sleep
- Speech
- Tingling in hands or feet
- Vision
- Weakness in arms or legs
- Weight change

2 Now please tick any specialty you feel you need further referral to:

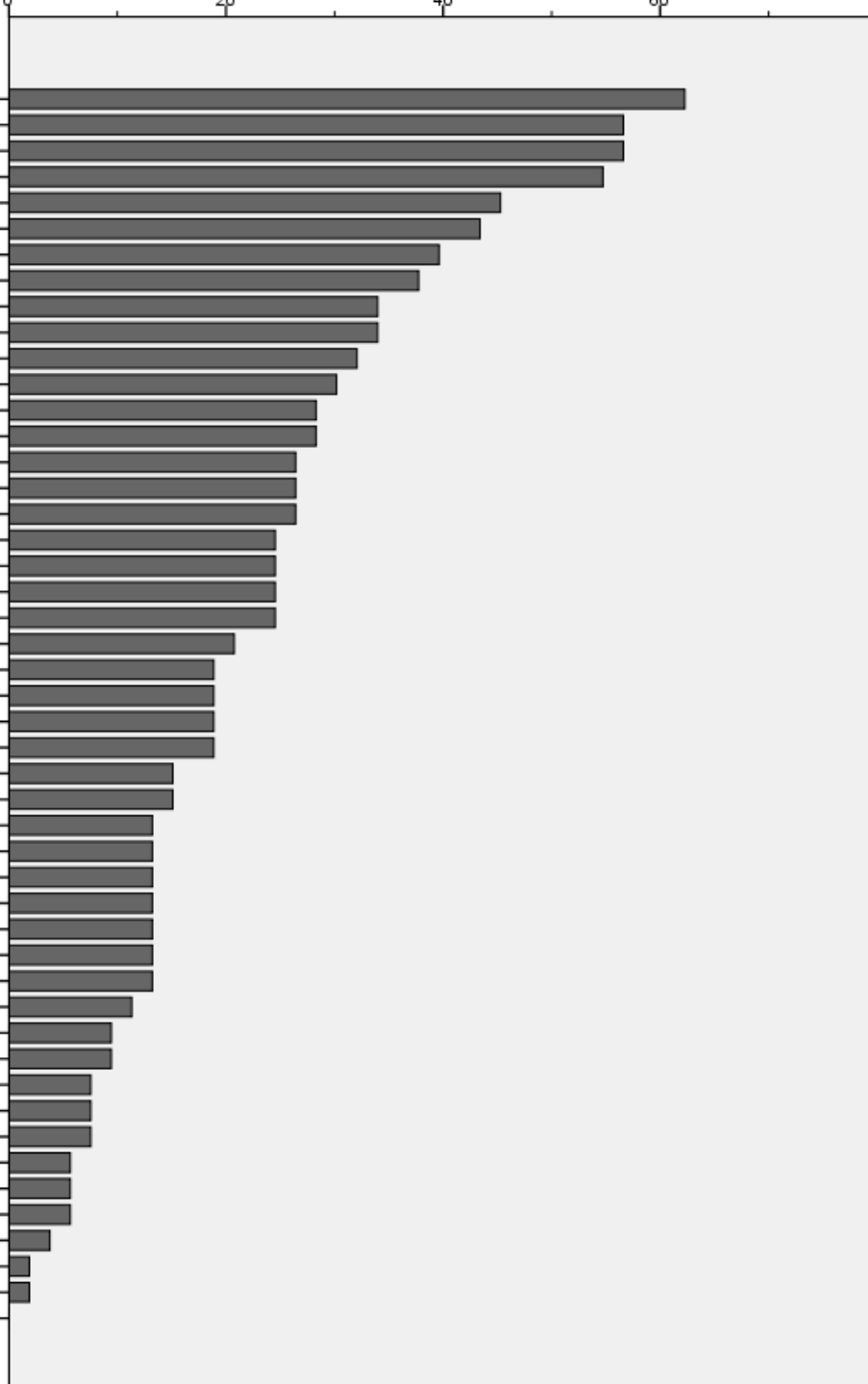
- Chaplain
- Dietician
- Palliative care services
- Physiotherapist
- Psychiatrist

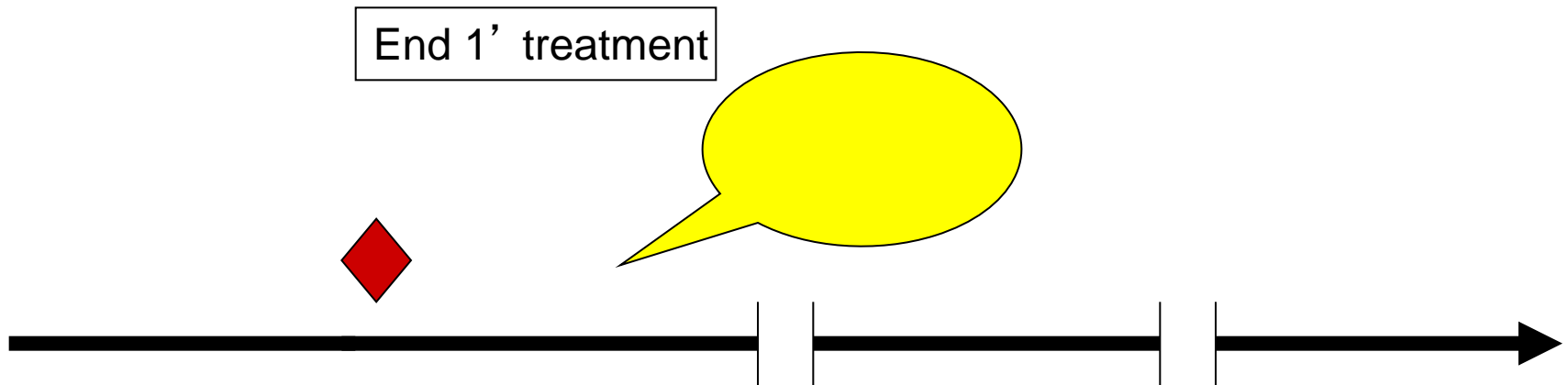
- Psychologist
- Occupational therapist
- Social worker
- Speech and language therapist
- Someone else (*specify below*)

Please turn over>>

Concerns listed on the PCI.

- Fatigue, tiredness or low energy
- Memory
- Fear of tumour coming back
- Concentration
- Sadness, low mood or depression
- Transport/driving
- Sleep
- Anger or irritability
- Headache
- Weakness in arms or legs
- Vision
- Personality changes
- Co-ordination
- Skin dry, or itchy
- Other fear, anxiety or worry
- Weight change
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- Nausea or vomiting
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- Difficulty relating to God
- Fever
- Loss of faith
- Child care





“Time of life” versus “time of disease”.

Patients and carers vary in how much they want to know.

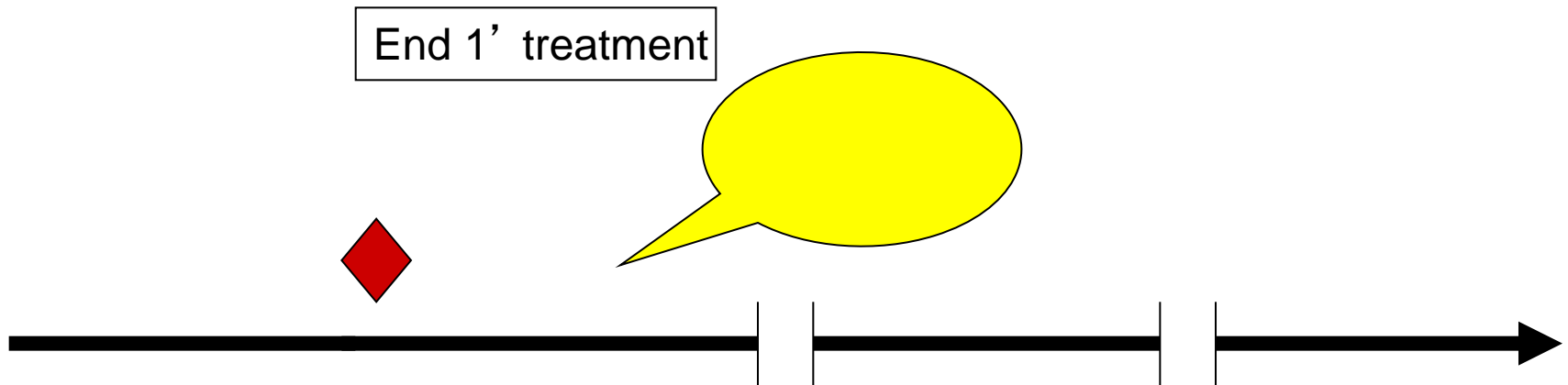
New symptoms cause worry and concern.

Follow-up scans can increase distress.

A feeling of “falling off the ledge” after treatment ends.

What questions do patients ask?

- What is the cause of my double vision? Should I get prism glasses?
- My left big toe is numb – is this related to the tumour?
- Do you think my heavy eyelids will go back to normal?
- I have become very angry and easily upset. Is this normal?
- Will I end up in a wheelchair?
- Are DVLA decisions based on a hospital report?
- Why don't I get another scan at this time?



Coping: stoicism, humour, disavowal, denial, positivity...

Hope: feeling well, altering perspective, selectivity...

Information: about the future, about the illness...

In a nutshell

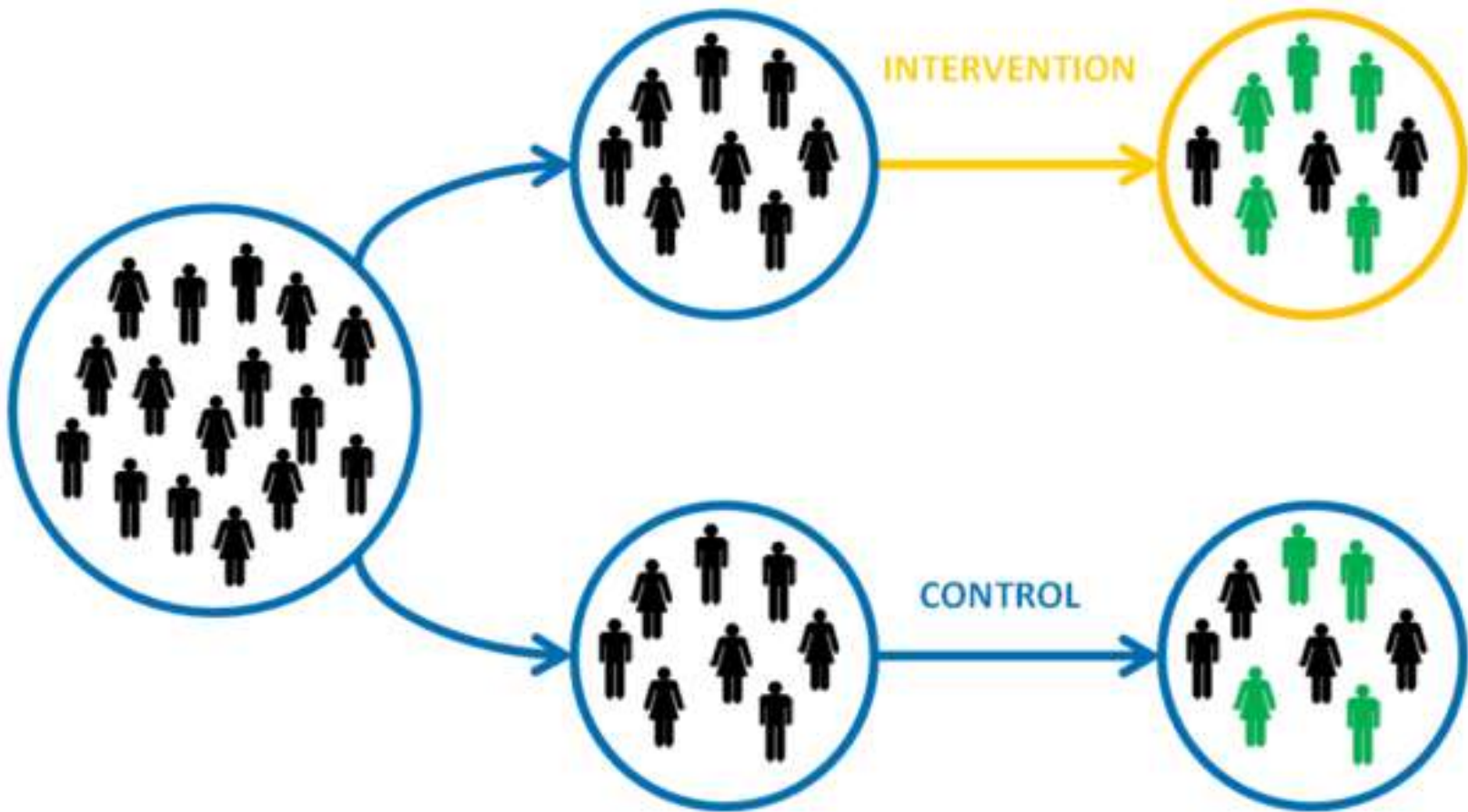
- Most psychosocial research has focused on diagnosis, primary treatment and stable outpatient follow-up.
- *Quantitative* studies tell us that cognitive problems, mood problems, fatigue and epilepsy are very frequent; and adversely affect QoL.
- *Qualitative* studies show a wide variation in information needs, response to diagnosis, coping strategies and maintenance of hope at this time.

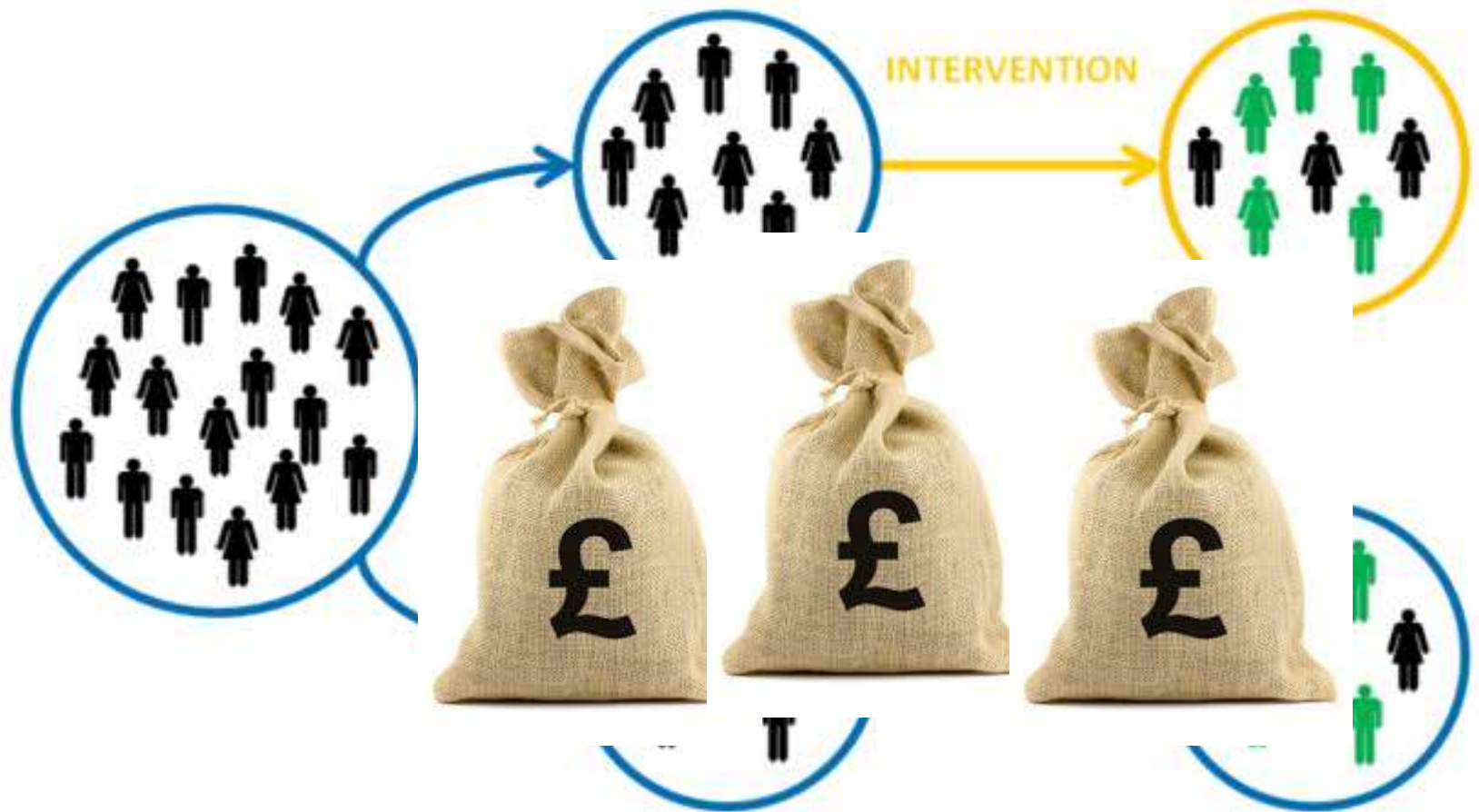
Psychosocial treatments?

- Assess the couple's perceived stressors, resources, coping strategies, and appraisals, and formulate a description of their difficulties in adjusting.
- *Tailor therapy to individual needs*: adopt information-giving, supportive, existential, problem-solving, cognitive-behavioural, and mindfulness “modules”.
- Aim to bolster existing resources, promote hope, and increase “time of everyday life” for each patient and carer, while reframing maladaptive coping / cognitions.









Psychosocial research is underfunded

- 2009: Cancer Research UK: “we will no longer fund psychosocial research”.
- NCRI 2011/12: Patients recruited to psychosocial oncology studies:
 - Non-RCTs = 3497
 - RCTs = 80
- We have made two applications to conduct an RCT of antidepressant benefit / harm in glioma: both rejected.

Practical barriers?

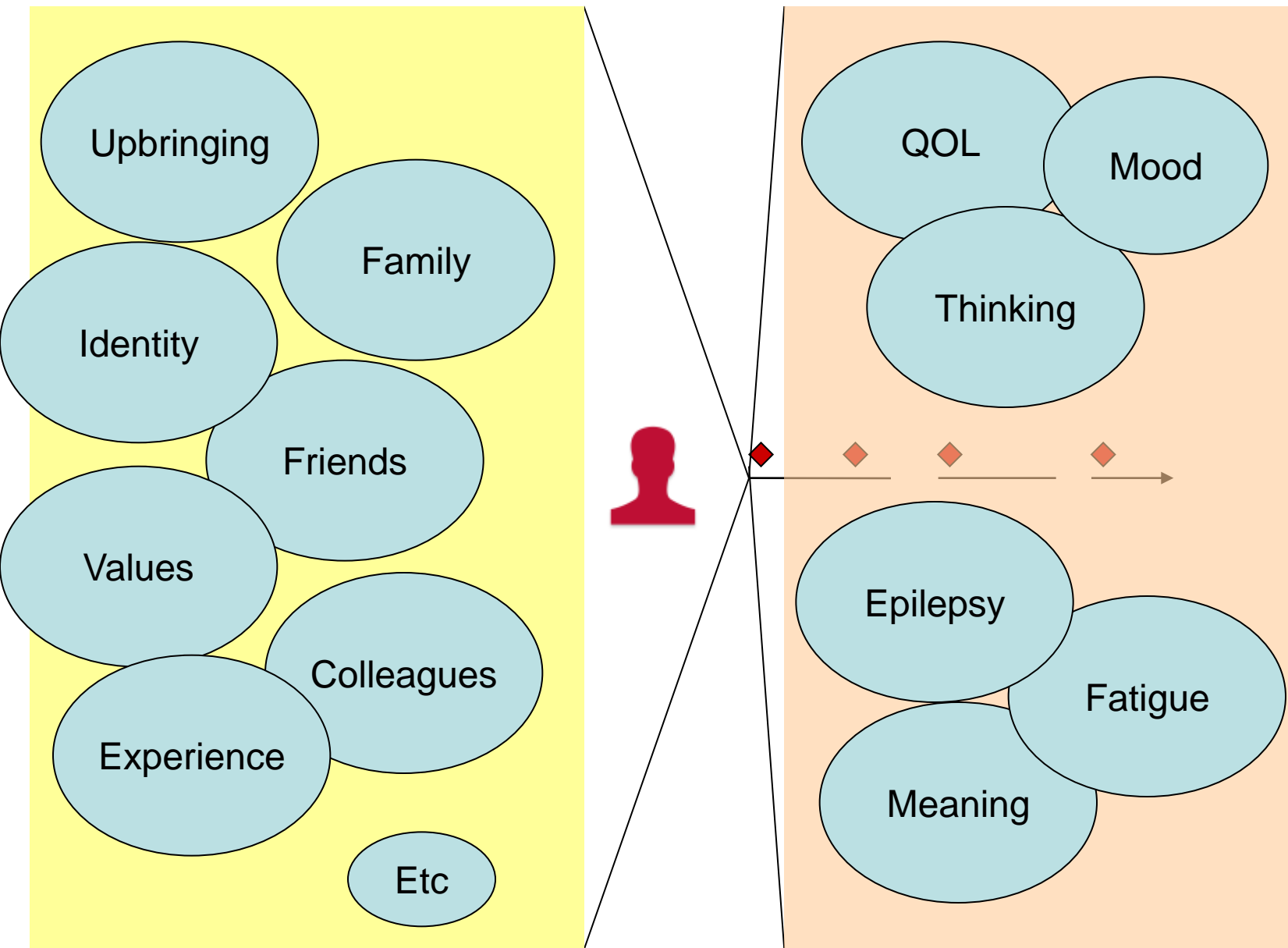
- Lack of support from major funders
- Disparate community (psychology, psychiatry, neurology, palliative care, nursing...)
- Lack of MDT system in follow-up
- Difficulty finding time in clinic to measure ‘soft’ outcomes
- Difficulty retaining patients in detailed studies
- Confounding factors make results hard to interpret
- Complexity of implementation...

Local opportunities

- Neuropsychology / neuro-oncology interest group at BNOS.
- SANON supportive and psychological care group.
- Scottish centres collaborating on studies on depression, epilepsy, fatigue, and communication at diagnosis.
- Edinburgh, Amsterdam, and Texas collaborating on monitoring patient concerns.

Summary

- Psychosocial research is vitally important as the balance of “care” against “cure”.
- Randomised trials of treatments are badly needed but require heavy funding.
- The Scottish neuro-oncology community is a global leader in this field.



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