



Shared decision making (SDM) in MS

Beyond the patient – physician encounter

Vicki Matthews

MS Specialist Nurse

MS Trust UK

SDM in MS

- Are we already doing it?
- What is needed to do it?
- What stops it from happening
- The 3 questions
- The Matrix, The Fog & The White Light
- The 3 C's
- AH - a case study



Shared decision making in MS beyond the patient – physician encounter

People with MS are not always
patients!

People with MS (PwMS) make 100's of
decisions every day

They made lots of decisions before talking to you

People with MS make decisions
every day, but before they
do.....

- **A**ctivating event
- **B**elief about the event
- **C**onsequential emotion & behaviour

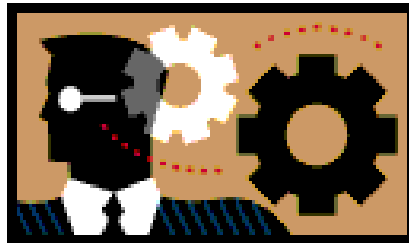


People with MS make decisions every day

- Discomfort with current situation
- Fear of failing
- Fear of a consequence
- Moving away from something painful
- Moving toward something pleasurable
- External change
- Conflict of values
- need for security
- need for approval
- Search for Meaning & purpose
- Search for Significance & recognition
- Mood emotionally driving the decision

But before we decide or choose what about our behaviour?

- Emotions can, and will, dictate to a large extent our behaviours or our “action tendencies.”
- Even if we don't carry out the tendency it can create or result in a disturbed consequence.



How might that behaviour show itself?

Anxiety

- Avoidance (of perceived or actual threat, risk)
- Seeking excessive reassurance
- Testing family, friends, professionals

Concern

- ✓ Facing up to perceived or actual threat, risk
- ✓ Seeking a reasonable and appropriate amount of reassurance
- ✓ Letting others share the burden with realistic expectations

Or like this.....

Shame

- Avoiding the gaze of others
- Hiding away
- Withdrawing from social contact
- Not articulating need
- Not asking for support/help

Regret

- ✓ Maintaining eye contact
- ✓ Holding your head up
- ✓ Keeping social contact
- ✓ Explaining the problem
- ✓ Accepting offers of support/help

SDM

- Concept has been around for a long time
- Implemented in last 10 years
- Much harder than people realise
- Not easy in practice
- Proliferation of patient decision aids/tools

Cochrane database systematic review 2012.....



Decision aids can be used when there is

- more than one reasonable option
- no option has a clear advantage in terms of health outcomes
- each option has benefits and harms that patients may value differently

Updated review of 86 studies found that when patients use decision aids they.....

- a) Improved their knowledge of the options
- b) Had more accurate expectations of possible benefits and harms
- c) Made choices that were more consistent with their informed values
- d) Participated more in decision making.

Cochrane Collaboration 2012

SDM works when

- Reasonable options on the table
- Personal preference is considered
- Personal preference is informed
- Risk are small
- Benefits are clear

Elwyn G, Laitner S et al BMJ 2010

SDM requires.....

- Problem definition
- Equipoise
- Organised as Options
- Ideas, concerns & expectations
- Information & Understanding checks
- Personal preference
- Deferment
- Review arrangements

Elwyn G, MAGIC Project 2012

SDM & Decision tools

Clinician

- Time constraints
- lack of applicability
- Patient characteristics
- Clinical situation

System

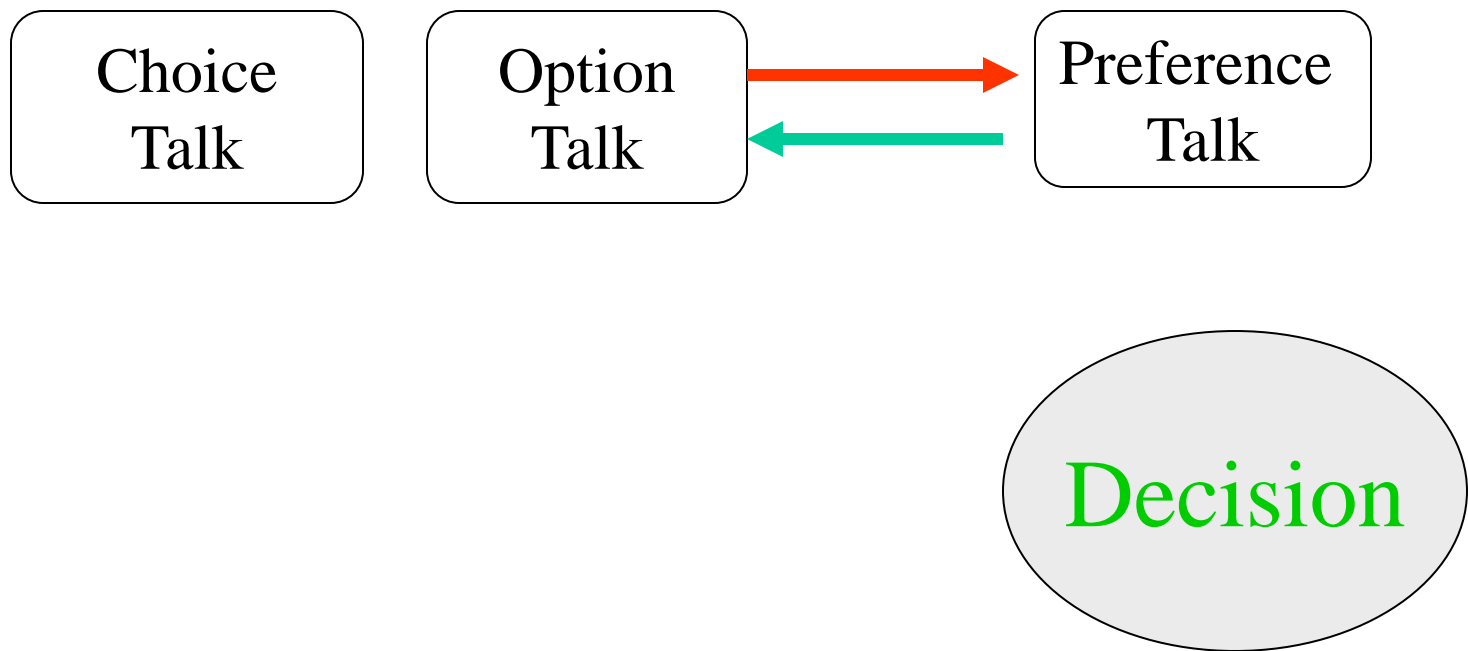
- Not designed to facilitate SDM
- Rewards other tasks

Patient

- New and unfamiliar role
- Fearful when given options
- Takes time and testing
- Capacity



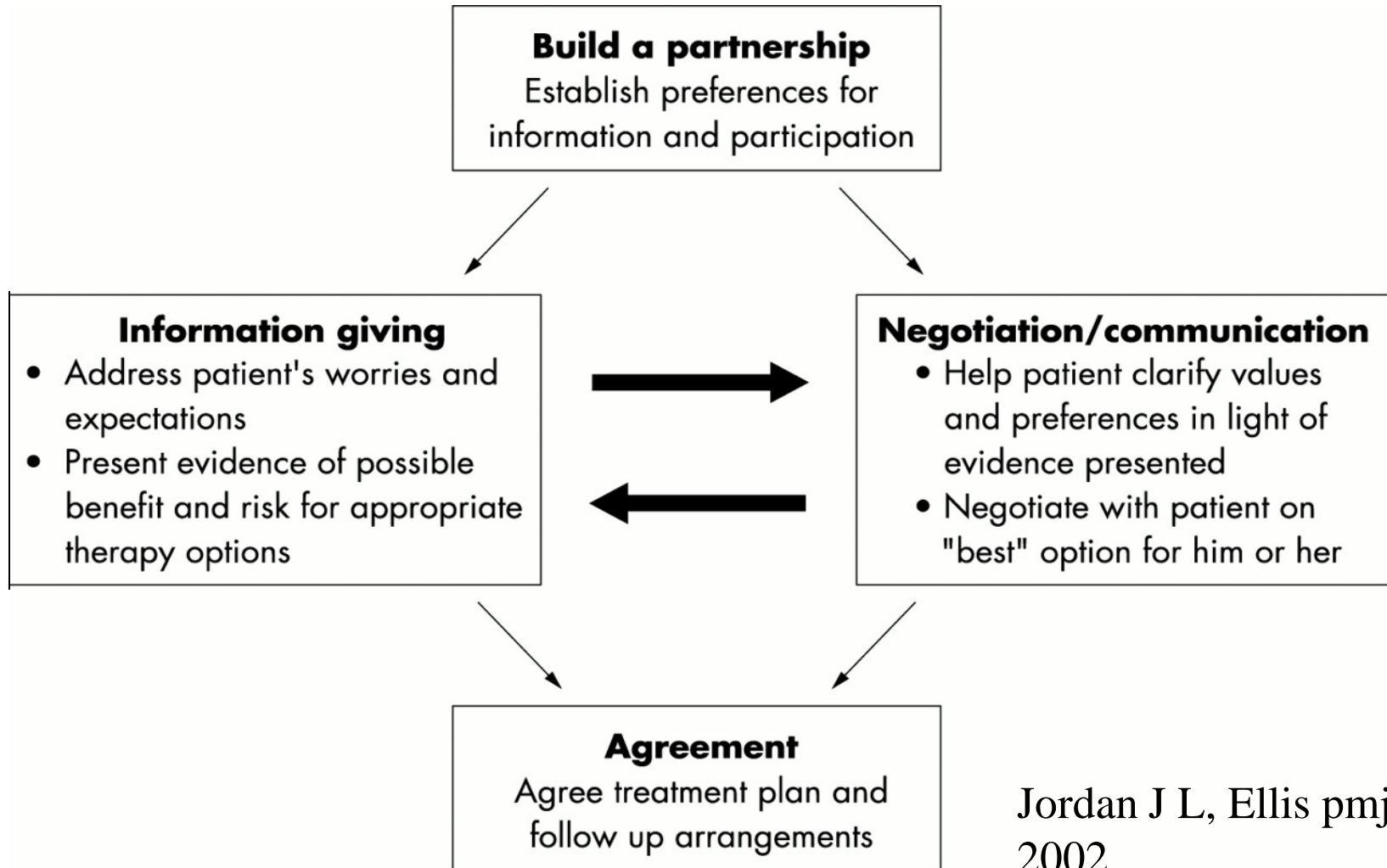
Patient Decision Support Materials



3 ?'s

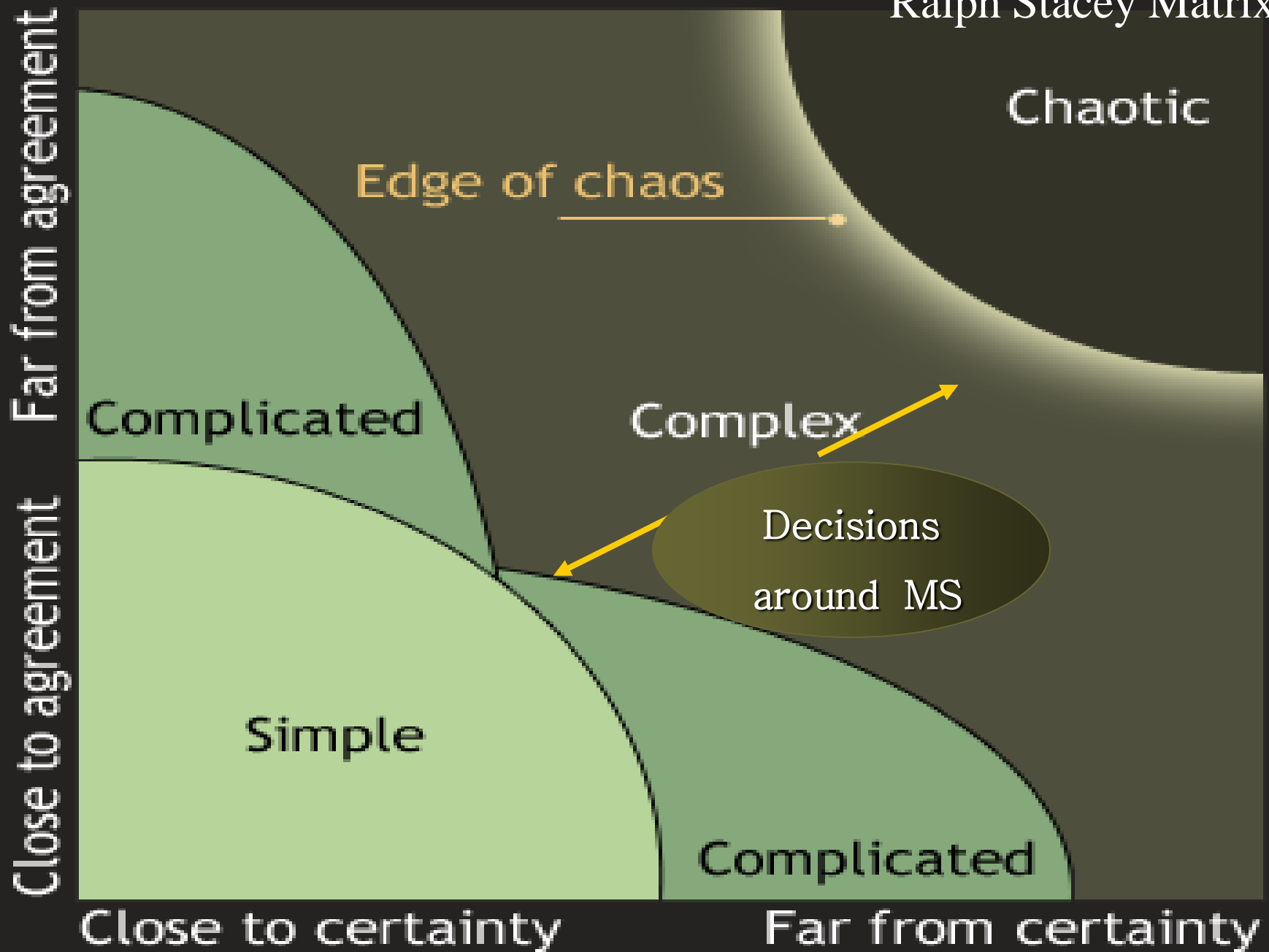
- ? What are my options
- ? What are the risks/benefits of those options
- ? How, and when, are the risks/benefits of each option likely to occur,

SDM & Concordance; are they one and the same?



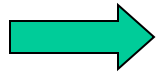
Jordan J L, Ellis pmj.bmj
2002

Ralph Stacey Matrix



Ralph Stacey Matrix

- Uncertainty low + disagreement low



Decision making can be simple

- Uncertainty & risk is high + disagreement is wide



Chaotic state

Area of complexity.....

The Healthcare FOG



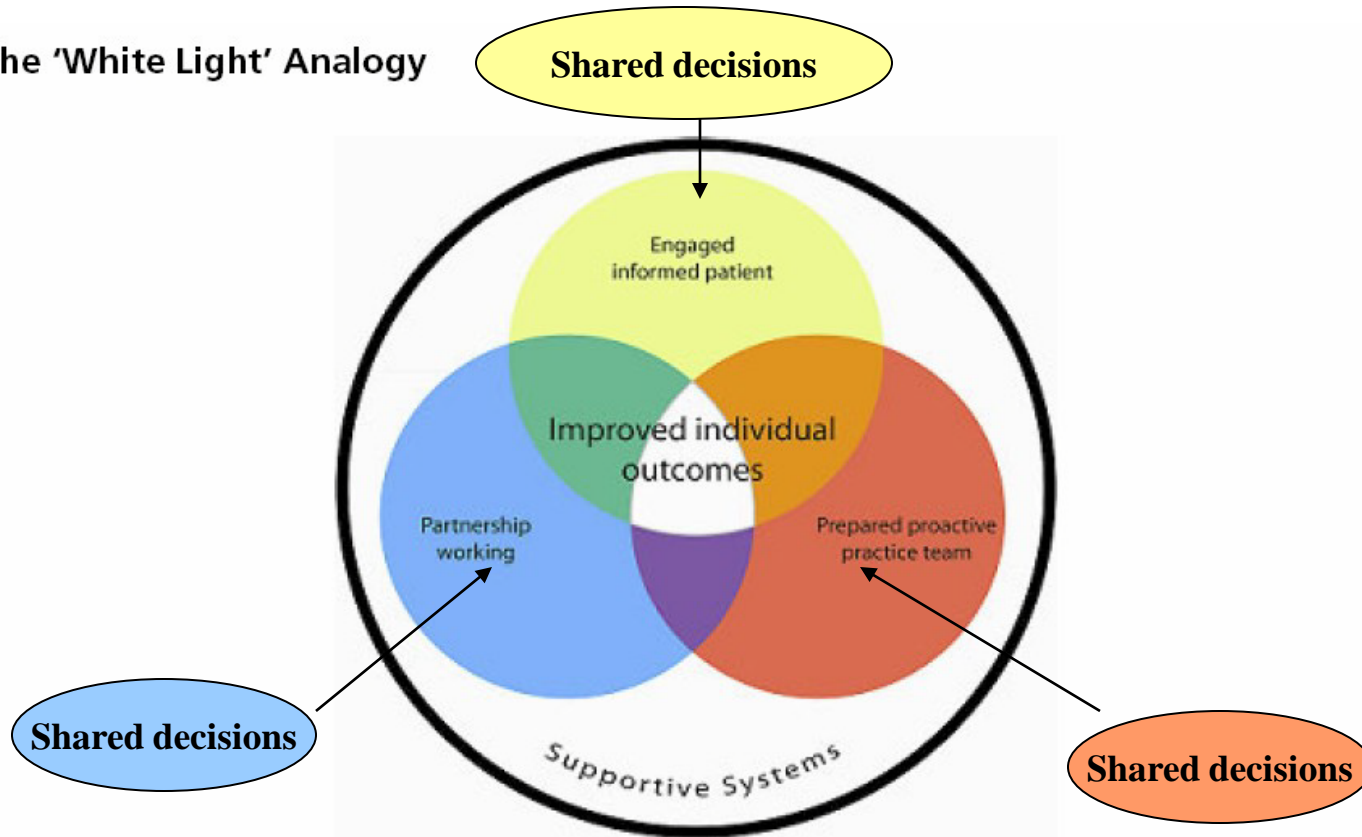
New Forest March 2012

THE FOG & SDM

- Coming out of the healthcare fog needs leadership
- The care you need and no less
- The care you want and no more
- No decisions made in the face of “avoidable ignorance”
- Every decision informed by professional & personal knowledge
- Patients shape the Healthcare capacity by revealing their preferences

THE WHITE LIGHT of care

Figure 2: The 'White Light' Analogy



Care Planning is a practical way in which these three components can be brought together in real life in general practice and primary care to improve the care of people with *long term conditions*.

2.4: Improving our *Support for Self Management (Self Care)*

*"Self care works, produces excellent outcomes, improves clinicians' job satisfaction, reduces workload and saves money. Most importantly patients want it."*¹⁸



The 3 C's of SDM

- Curiosity
- Competence
- Courage

Al Mulley Dartmouth Hitchcock Medical Centre 2009

How many decisions in one day, one week, one life time?

A Case Study

- AH
- Female
- 27 yrs
- Married
- Mother had MS
- High level IT exec
- Diagnosed 2008
- Seen MSSN clinic 2010



- Mum's MS
- Dad's alcoholism
- Husbands anxiety
- Mental health
- Sexual health
- Planning a family
- Access to work
- Fatigue management
- Symptom management
- Self managing
- Navigating the healthcare system
- Managing MS with wider health care team
- Treatment options

.....and the life yet to be lived

“We met today at the..... I know you see a lot of people every day so you may not remember me specifically.

I just wanted to email you to say thank you for your time today. As I said earlier, the hour we spent together was the most helpful and positive session I have had since being diagnosed with MS.

I didn't realise quite how lonely and isolated I had been feeling until I left today and thought it all through.

I push it to the back of my mind in how frightening I have found all of this and just knowing I am not going mad is good!

AH.



The Journal of a Disappointed Man

"I am only twenty-eight, but I have telescoped into those few years a tolerably long life: I have loved and married, and have a family; I have wept and enjoyed, struggled and overcome, and when the hour comes I shall be content to die"

"To me the honour is sufficient of belonging to the universe
.....such a great universe, and so grand a scheme of things.

Not even Death can rob me of that honour. For nothing can alter the fact that I *have* lived; *I have been I*, if for ever so short a time

Fred Cummings 1889 -1919