

What do patients (and families) want from a rehabilitation prescription?

In collaboration with
Grace Havard
Duncan Buckley
Shan Martin
Kerry Staab
Jo Horton

The current format is too complicated for patients and families

Going home is 'traumatic'...

Grace...

- Rehab prescriptions are very inpatient focused when in fact I think they are more needed once you are discharged
- Having a plan in place (for both physical and physiological rehab) would, in my opinion really minimise the negative feelings/experiences patients experience after discharge.

Kerry...

- My thoughts are... ongoing rehab and support as an outpatient are paramount! I feel goals are important but have to be manageable.
- For us now five years down the line getting back into the workplace is a mountain which challenges so many facets of Ben.
- Family support I feel is also really important to help keep life in some sort of perspective for all. I know from personal experience how broken our family became as a consequence of Bens accident ... I feel the breakdown of our 'family' affected Ben which was the last thing he needed on top of his other 'losses'

Shan...

- Seems very focussed on the 'prescription' for whilst you are in inpatient.
- For me the biggest issue is when you get out.
- The benefit of having a coordinated rehab plan, which is maintained throughout the rehab months/years would be major focus for me, which includes as Duncan has suggested the psychological support for the patient as well as family.

Duncan...

- I would certainly emphasise the psychological aspect of trauma, and finding some ways (clinical and non clinical) to understand the changes to an individual's personality; either through a patients and/or relatives focus.
- I posted this up on the After Trauma forum today (<https://www.psychologytoday.com/blog/think-act-be/201610/7-ways-survivors-can-grow-after-trauma>) which is quite accurate and important for trauma survivors and their mental coping mechanisms.

Concerns (*identified in patient/carer interviews*)

- Generally being worried
- Feeling emotional – patient and family
- Pain
- Anxiety
- Motivation, appetite, impulse control and energy levels
- Memory
- Exercise tolerance
- Scars
- Problems with family relationships
- Recreation/ leisure
- Living healthily and looking after self
- Unemployment insurance
- Staying in work

Injury related information that patients/carers wanted (*identified in focus group*)

- Injuries sustained
- Information on symptoms and if that is normal?
- Prognosis - What to expect (especially when going home)
- Peer support – talking to people with similar experiences/injuries

Patients wanted recovery information in terms of -

- Key target dates e.g. goals and steps to achieve them
- Planning towards discharge home and what to expect
- Where to get equipment from
- What services to access and how to access them

Patients wanted recovery information related to -

- Weight bearing
- Pain
- Mood
- After care hospital
- Peer support
- Relationship with family
- Who to contact post discharge
- Work
- Driving
- Welfare benefits advice
- Legal advice
- Community services
- Going on holiday
- Insurance

The importance of family and children

- Family may need psychological support
- Psychological support in MTC / TU / Community
- Post Traumatic Stress Symptoms (patient and family)
- Older patients – social isolation

Rehabilitation prescription – what should it look like and how should it be delivered?

- GP needs to receive information, at least medical discharge information
- Clinicians should consider providing information which is accessible, e.g. on-line vs paper
- Updating information – track progress
- Written in plain English

What I wish someone had told me...?

- This is very difficult.
- Acceptance that you will never be as you once was and just to accept how you are now. Do the best you can and do not be scared to tell people if you can't do something or need help. Most of us are proud and don't like to lean on others. I still have pains, aches etc after nearly 4 years and sometimes put on supports and people forget and say "oh what have you done" and you have to admit nothing it's from the accident.
- I accept that my concentration is bad, my multi tasking is practically non-existent now but you need to look on the positive side of everything. You are alive so keep fighting and you will get there, but be realistic don't push yourself too much.
- To summarise, realistic aims, think positive and keep going as your new amended self.

What I wish someone had told me...?

- What first comes to mind is that it would have been easier for me to prepare for coming off painkillers if I had known the nature of the withdrawal symptoms in advance so that they didn't come as a shock.
- Wish someone had told me that when they said 'it will take time to recover from this' they meant a really long time, not just a few days or weeks. I didn't understand for the longest time what 'time' really means when doctors say it. And it doesn't help that the rest of the world goes on thinking it'll be just a few days or weeks.

Summary

- Impairment list?
- After discharge
- Patient vs therapy needs



- http://www.bartscharity.org.uk/?gclid=CjwKEAjw-uDABRDPz4-0tp6T6IMSJADNoyPbZl5tE2PFz7F0k6dCdMzH8dW-Npifq_JyXvOulOHlthoCpDbw_wcB