## **Patients and Carers**

## **MTC-27**

## Birmingham 24 September 2015

## Key points

- Return home is a monumental date for the patient. Very helpful to give a target date.
- For those with lower limb fractures, return to weight-bearing also a key date in rehabilitation. T&O should try to give a target date.
- Provide patients with a written care plan including key target dates!
- Sudden transfers very distressing for patients. Notice and explanation should be given if at all possible.
- Staff in Trauma Units are not experienced in managing patients with polytrauma. We need more exchange and education between MTC and TU in network.
- Both in and outside hospital there can be a lack of accountability with no one taking responsibility. Within MTCs this should be the named Major Trauma Consultant. Within TUs patients must have a named consultant. Ideally, in the TU this will be a rehab consultant but many TUs do not have this facility and so a consultant from an acute trauma specialty will need to take responsibility.
- Patients leaving hospital (falling off the cliff) face a number of key challenges:
  - Equipment and resources
  - o Disability prejudice
  - Access issues no temporary "Blue Badge"
  - Psychological factors
  - Workplace support and vocational rehabilitation. Phased return.
- There is not a shortage of equipment in the NHS. Getting it is the problem!
- Many patients have no memory of the accident or their initial time in hospital. Many would like this information (to fill in the gap).
- Psychological factors are very important:
  - Patients feel guilt for putting their family through hell
  - Loss of self worth
  - Family (partner and children) may also need psychological support.
  - Psychological support needed in TUs and MTCs
  - Resources for community psychological support need to be in place prior to hospital discharge
- "Process and system" within the NHS must never forget the "self".
- For the patient, their personal experience is far more important than measuring "effectiveness and safety"
- Focus group effective way to get feedback from patients.

- Patients are left "in limbo" after discharge.
- Patient feedback lunch with the CEO is a good way to change the system!
- Patients would prefer a single clinic for review: Move towards multidisciplinary Major Trauma Rehab clinics
- Newcastle model has this clinic embedded in fracture clinic, led by physiotherapy and supported by consultants
- Travel: No issues with travel for acute care. Variable for rehab. Some prepared to travel good distance for the best rehab in region. Others prefer care nearer to home. Should this be established before discharge?
- Patients want to, "Get answers". Fracture clinic provides: time for walking, driving, working and healing. PT and OT provide ADL's
- Following discharge, frustration is a common emotion! Getting access to PT, equipment etc.
- Pain no clear guide after discharge. Can we do more to reduce this? Can we discharge patients with a clear and written analgesia plan? Is this a role for pain team and pharmacy?
- MTN communication. Networks must have meetings of Trauma and Rehab coordinators from TUs and MTCs. Minimum = every 6 months
- The elderly. Key injury facts from Southampton study:
  - 25% of major trauma patients >65 years have a missed injury
  - 80% of these have 1 missed injury, 20% have 2 or more
  - $\circ~$  A third required surgery for the missed injury  $\,$  spine and head the most common.
  - A large MTC will miss an injury in the elderly every 10 days!
  - $\circ~33\%$  had low harm, 50% moderate and 15% severe harm
  - Reasons injuries missed:
    - Wrong pathway: elderly don't present as major trauma
      - Triage
      - Only 25% had trauma CT
- Trauma coordinators: what makes things better for patients:
  - Early interaction with relatives
  - Business card, mobile number, email + useful websites
  - $\circ$   $\;$  Hospital information leaflets for MTC and all TUs in network
  - Admission record early to GP
  - Regional coordinators network group
  - Point of contact post-discharge
  - Discharge booklet
  - Could information sheets, booklets etc. all be available on web too?
- Patient stories are powerful. Use them more
- Day One Charity provides:
  - Peer support which is trained and matched to patients
  - Welfare benefits advice
  - Legal advice
  - Advice on self-management
  - And supports:
    - Training and education in trauma
    - Equipment
    - Research

- Legal advice needs to be:
  - An opt-in service
  - $\circ$  Free to all
  - Comprehensive not limited to personal injury claims
  - $\circ$  Assured
  - Available in all MTCs
- Legal advice has the potential to fund enhanced rehab for many patients and NHS needs to work with the legal profession to achieve this.
- Children and their families:
  - 50% parent experience symptoms of PTSD
  - 50% parents suffer low mood, mainly related to social dysfunction
  - Major Trauma in children has a significant emotional impact on parents
  - Psychological support for parents is not adequate
  - Psychologist meeting the parents likely to be helpful
- Patients and carers need and want to understand their injuries. How can we achieve this? Need to produce bespoke reports in everyday language. Needs a series of drop down menus for each of the common injuries. The amount of information required varies. In general, limited in the short term and more detailed in the long term.
- Single point of contact essential for good communication with patient
- We need to reduce logistical problems as much as possible:
  - Visiting hours
  - Hotel info
  - $\circ$  Where to find food
  - Transport & parking
  - Hospital accom.
  - Constant ward / unit
  - Legal, benefits etc.
  - There must be a clear medical plan
  - Inconsistent information must be avoided
  - Named nurse in charge
  - Let relatives know when patients going for tests
  - Right information for right part of journey
- Transitions of care we must be able to handle these better
- Patient diaries in Critical Care can these be extended to the Major Trauma Ward
- e-rehab prescription we need to make it work!
- Look at "Discharge Advocats" as used in USA. Maybe part of MT coordinator role?
- Patient consultation with pharmacist pre-discharge. Increases compliance and decreases medication errors.
- After Hospital Care Plan. Every patient should have one!

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