Putting the Patient at the Heart of Care

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About me

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Overview of presentation

- Issues for people with complex needs (before, during & after admission)
- Key roles for the MDT
- Central role of the patient
- Surgical pain
What are our goals?

- Optimum patient experience
- Optimum patient outcomes

The whole team needs to be good at their role.

How do you empower the patient to be good at theirs?
Defining our terms: ‘patient’

What do we mean by ‘patient’?

When do you start and stop being a patient?

Demedicalise the approach – person not patient centred
Defining our terms: ‘empowerment’

Who empowers the patient? You, them or both?

What does the empowerment process involve?

How do you recognise empowerment?

Why is it important?
Defining our terms: ‘where, when and what?’

Where does empowerment occur – just in clinics and hospitals?

When does empowerment begin and end?

What are we actually measuring?

If unsure about any of these questions, how does an MDT begin to promote patient empowerment?!
Complex patient needs, difficult choices

- *Medicines interaction: eg antibiotics vs biologics in RA*
- *System control vs pain control: eg warfarin vs painkillers*

*Role of MDT: ask your patients, respect their preferences.*
Know your patient, but know their environment too (1)

- Social model of disability
- ICFDH: approved by WHO 2001, is a model setting out all health and disability components of functioning
- Patient’s functional environment after discharge
- Communication barriers (cognitive, sensory, language related) are your issues too
Know your patient, but know their environment too (2)

Disabilities might therefore include:

- Transport
- Isolation (reduced mobility as risk factor for obesity, depression et al)
- Nutrition
- Navigating and using the home / falls prevention
- Fuel poverty
Empowerment = patient focus

A changing role for patients:

From: ‘You’re sick, or damaged – we’ll fix you’

To: ‘We’re going to work together and you need to play an active role’
Let’s make it real: Nick’s story

http://www.youtube.com/watch?v=8INil_wfXaQ&feature=c4-overview&list=UUxYcCcu3o22xiRxy-UvQHLw
A patient party!

- Identified resources needed by patients & carers
- Information designed and tested by patients
  - Patient story DVD emphasising the patient role
  - Generic patient leaflet ‘My role and my responsibilities’
  - Use of voluntary sector best practice
Patient Empowerment

‘My Role and My Responsibilities’

Launched at ER Summit by Health Minister

Over 100,000 leaflets ordered by providers
It’s the patient’s journey

- Key word is ‘My’
- Key concepts are ‘active role’ and ‘responsibility’
- Patient responsibility: a conditional deal, steps you can take to do more for yourself
- Most people buy that: wouldn’t you…?

‘I didn’t know I had a role’ Nick
Eight Top Tips for Patient Empowerment

Quality assured information soon after referral

Ensure that the person knows what is involved and is comfortable with what is expected of them

If patients own the process at this stage they will drive it more strongly later

1. Having ownership of the decision to opt for surgery: If the patient has made an active decision in electing for surgery, rather than having ‘been referred’, then this sets the tone for an active role along the rest of the care pathway (see case study: Shared Decision Making in Urology on page 42).

2. Good communication from the GP at the time of referral about what to expect from enhanced recovery: If expectations are aligned at the earliest stage, the whole journey is less stressful for the patient, who in turn feels more in control and better able to play their part in their recovery.

3. Quality assured information soon after referral: This might be provided by the local service, with a view to a face to face follow up (e.g. with a specialist nurse) to ensure that the person understands what will be involved and, most importantly of all, is comfortable with what will be expected of them. If patients ‘own’ the process at this stage, they will drive it more strongly later.

4. Practical support in advance to make post-operative recovery less difficult: Many providers of enhanced recovery invite pre-operative patients to the hospital to meet staff and learn coping and recovery techniques such as physiotherapy before post-operative pain and distress make absorbing this new information more challenging.

5. Peer and/or family support: Relevant patient groups play an important part in reinforcing positive messages of support around self-management, via a helpline service, written information or by putting people in touch with others who have benefited from self-management. Involving carers, partners, other family or close friends can also help provide a network which gives the person confidence to feel they will have support even when not in direct contact with their health professional team.

6. Positive reinforcement from the anaesthetist and surgeon: It is extremely reassuring for the patient, before and during admission, to hear their specialist health professionals describe enhanced recovery techniques as normal in getting the best outcome for patients.

7. Knowing who to ask: Whether the patient be at the pre, peri or post-operative stage they will have questions arising or anxieties forming which, if left unattended, could jeopardise their recovery process. It is one of the most empowering things of all to feel confident that at such times you know where you can turn to for answers, advice or support.

8. Anticipating a rapid recovery positively: Whether it is early post-operative mobilisation in the ward or making the journey home, the patient will be more able to get better sooner if they have previously considered all that will be involved and know that they can access support to deal with the unexpected.

THE BARRIERS AND ENABLERS TO AN OPTIMUM RECOVERY

- Patient’s level of confidence
- Getting the right information at the right time
- Getting easy access to support along their journey, or for social and practical issues when at home
- Knowing how to cope at home whilst continuing recovery
- Social care arrangements being made in the first part of the pathway is not only reassuring for the individual, but addresses an issue which unattended can significantly increase the risk of delay in discharge or unplanned re-admission
- Empowering people to help themselves throughout the pathway becomes a key determinant in the overall quality of care ultimately experienced as a result of enhanced recovery.
You can generate, not just capture, patient empowerment:

‘Patients have a better understanding of their need to engage in their own roles and responsibilities. It has prompted them to ask more questions.’

Health Professional

93% of hospitals said they would continue to use the leaflet
Pain management and Peri-operative medicine (1)

- Acute pain impacts on recovery from surgery in many ways. Impaired ventilatory function, surgical stress response, wound healing, delayed mobilisation and discharge.

- Poorly managed acute pain is a key risk factor for the transition to chronic pain (Lavand’homme, 2011)

- Chronic post-surgical pain is common, occurring in 10-50% of all surgical interventions, and is procedure-specific (Schug, 2011)
Pain management and Peri-operative medicine (2)

- People with chronic post-surgical pain (CPSP) have a poor quality of life, where impacts can include loss of employment (25%) and psychological problems (50%) (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Taylor et al., 2012)

- But acute post-surgical pain can be foreseen: PROSPECT - (www.postoppain.org) – has developed evidence-based analgesic approaches for many common surgical procedures (Neugebauer, Wilkinson, Kehlet, & Schug, 2007)
Pain: what is needed going forward? (1)

- **Preoperative risk stratification, and procedure / patient specific intervention**, applies to pain as to other significant outcome measures such as mortality or cardiac morbidity.

- **Training**: 2008 CMO report had a chapter on pain management. Recommended introduction of education on chronic pain to syllabus of all HCPs - still not achieved.

- FPM has a web-based multidisciplinary e-learning programme (e-Pain) - numerous modules, completion of which could form part of this training?
Pain: what is needed going forward? (2)

- **Audit / standards**: need a review of national acute pain management practice, including procedure-specific standards, to achieve better outcomes for our patients (White & Kehlet, 2010). See PAIN OUT [www.pain-out.eu/](http://www.pain-out.eu/)

- **Guidelines**: where clear evidence exists, national guidelines could be developed for optimising perioperative analgesia, with specific tools for the prediction of acute and chronic post surgical pain, & evidence based treatment algorithms to minimise risk
How you can support empowerment (1)

- Shared Decision Making throughout the pathway
- Signpost to reliable information and peer support eg patient groups to support self-management
- Involve family / carers actively: 2 heads better
- Help people anticipate & interpret post-surgical signs eg redness, itching
How you can support empowerment (2)

The power of tailored, accessible information:

- Information only has value when the recipient has internalised it
- Provides confidence, security and a positive approach
- For a range of providers too, extra value in quick access to patient records eg ambulance services
- See work of Professional Record Standards Body

www.theprs.org
Hold a Pain Day?

- In 2013 UCLH held a Pain Day, inpatients asked about their pain – 381 responses collected by 50 volunteers in 2 hours
- 50% of patients said they were currently in pain
- When asked how much pain affected their ability to do things they wish to, eg sleep, move, read, patients with LTCs were most affected scoring 7.49/10 (10 = pain stopping them completely). Patients who had operations and those with cancer scored 6.41 and 5.46 respectively
Summary and conclusion

• As Pain Day illustrates, pain is widespread and has significant impact

• But the good news is that exercises such as this, putting patients at the heart of care, are empowering for both staff and patients

  • “Alone we can do so little; together we can do so much”

    Helen Keller

Thank you