

THE CONTEXT OF SELF-MANAGEMENT OF MEDICINES for pain and related nausea, constipation & drowsiness

INTRODUCTION

- National study
 - We are developing a toolkit - package of resources to help patients self-manage their pain medicines and related side-effects. Patients would be instructed to use the resources by a CNS. The overarching intervention will be more than just a toolkit but a process too that the nurses can use to help assess and educate patients to make appropriate everyday choices regarding their medicines.
 - We will go on to run a trial, to see how well it might work in practice
 - So, we'd like your help to discuss with us the issues for you in managing your pain medicines and related side-effects and to provide suggestions about the package of resources, so that we can shape it to meet your needs
- Context
 - Helping individuals to successfully self-manage medications in the community
 - Self-management of pain medicines may lead to better pain and side-effect control
 - We know carers need information regarding medicines too, and some are heavily involved in helping with medicines, which is why we have actively sought their views too

SELF-MANAGEMENT SUPPORT IN RELATION TO MEDICINES

Our study focuses on self-management of pain medicines and the related side-effects of nausea, constipation and drowsiness. We are looking at the strong painkillers called opioids, some examples are morphine, oxycodone, buprenorphine and fentanyl.

I'm here understand the day-to-day difficulties and decisions that individuals (and their carers) have to make when dealing with their pain medicines.

We have been working to the following definition of self-management support as:

Assessing, planning, and implementing care to support the individual to be given the means to deal with their illness or its effects. With self-management of pain medicines this may require helping the individual with things like getting prescriptions and supplies, storing medicines, administering them, monitoring symptoms and adjusting doses. When self-management is supported by nurses, individuals can face these practical difficulties and identify areas where they need further support. So it's about being provided with the means to master or deal with problems, by learning new skills, rather than giving up control of them to others.

ROLE

What role do you play in managing your medicines?

- Could you tell me about how you like to participate?
- What are the things that you expect to have to do so that your pain and any side effects of pain medicines are well managed?
 - What do you choose to do, and what do you choose not to concentrate on?

What are the things people do to help you with your medicines? (What role does your carer play?)

- Do any of your family or friends help?
- What specific help do they provide?

How helpful have your palliative care specialists been in educating you about your medicines?

- What has been helpful?
- What hasn't been helpful?
- Is anything missing?

Do you need any additional help at all?

- What should this help look like?

PRACTICAL DIFFICULTIES

From the literature we know that the issues on these cards have been problems for some people. Getting prescriptions, obtaining medicines, understanding, organising, storing, scheduling, remembering, administering, monitoring.

- Could you pick any that are important to you and provide some examples of the problems you've encountered?
- What are the kinds of things that would better support you for dealing with those problems?

DEVELOPMENT OF THE INTERVENTION

The kinds of things we know that are helpful from the research are:

1. Initial assessment – understanding of what's being taken and why, side-effects, offsetting of intended vs unintended effects of medicines, assessment of fears regarding medicines taking (educational messages to address these barriers)
2. Information giving – verbal, written and DVD, when and where to go for advice/support if things aren't working
3. Joint planning between nurse, patient and carer - setting of short term goals (e.g. improved pain control at night) and planning of ways to achieve the goals
4. On-going support - weekly phone calls or visits by a CNS over approximately 4 to 6 weeks, including practical support regarding getting and maintaining supplies of medicines

What we are thinking is if we develop an intervention (with the specialist healthcare professionals) that combines all these elements then we may be able to better prepare individuals to manage their medicines.

- What do you think?
 - What do you think would be the most important elements for you?
- Recognising that time with specialist nurses can be limited what are the most important things that you would want to talk through with him/her as opposed to being left written materials on, so that you are better prepared to deal with your pain and the side-effects?

Thank you so much we've had a really useful discussion on your experiences of self-management of pain medicines and related side-effects. We will take your information and merge it with the information we gain from specialists to tailor the toolkit to meet patient and carer needs. Is there anything that you would like to add that you feel has not been discussed already?