

MID TRENT CANCER NETWORK

A REPORT FROM THE 'Don't forget the carers'

A Workshop to develop an Information Prescription for Carers

14th November 2007

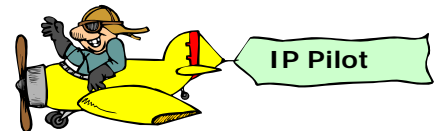


Context

Following the submission of a bid to the Department of Health at the end of December 2006 the Mid Trent Cancer Network (MTCN) became a pilot site for information prescriptions.

Prior to submission the draft bid was discussed and approved by the Network Patient Information and Communication Group at its' meeting in December 2006.

The final bid was also agreed by and signed off by the Chair of the Mid Trent Cancer Network Management Board. The Network Management Board further endorsed the project at a meeting in January 2007.

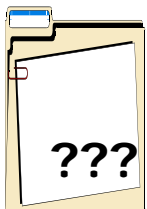


Since January information prescription (IP) has been developed, tested and implemented within three cancer pathways; head and neck, lung and gynaecology cancers across the MTCN. To date over 220 IPs have been issued to people with cancer.

A message that has emerged during this work has been the need for not only patients to have high quality appropriate information but also carers. To explore this further a workshop was held with patients, carers and professionals to explore:

- If this was a good idea?
- What an IP for carers might look like and contain?
- How it might work in practice?

What is an Information Prescription?



At the outset of the pilots there was no definitive guidance or definitions for what an IP was or should do – in effect the pilots had a blank sheet of paper!

Cancerbackup provided a very helpful definition which started the thinking behind what an IP for people with cancer in the MTCN might look like and include.

“A source of personalised information that lays out clearly and simply the salient points about an individual’s consultation with a healthcare professional about their diagnosis, treatment and/or care plan and points the way to other relevant sources of high quality information and support. It is designed to improve the dialogue between patients and health professionals and enhance the valuable face-to-face time within consultations”.

A workshop for carers?

Previous research in the MTCN looking at information pathways highlighted the need for high quality, appropriate information for carers as well as patients. The recent work evaluating the patient IPs has also highlighted the variance in how information is shared and used between patients and carers.

A workshop was held attended by 37 people including 7 carers, 6 patients and 24 professionals.

Key questions explored within the workshop were:

- Do carers need/want an Information Prescription?
- What should a carer IP look like and include?
- How should the information be prescribed and dispensed?

The range of professionals who attended included:

- Clinical Nurse Specialists
- Community Macmillan Nurses
- Hospice nurses
- Lead Cancer Nurse
- Occupational Therapist
- Cancer information specialists
- Welfare rights advisor
- Patient and public involvement facilitator

The Design of the Day

The day was designed to support the maximum contribution from everyone and to encourage creative thinking that would inform the development of the carers IP.

The Morning

The morning sessions started with two presentations. Elaine Wilson the MTCN Nurse Director explained to participants the background to the IP pilot and the concept of developing an IP for carers.

A second presentation was then given by Judith Rookes. Judith travelled the cancer journey with her husband who died as a result of cancer 2 years ago. She shared a personal experience of supporting and caring for her husband in the later stages of his journey and the difference it would have made if she had received 'better' information and signposting both to her experience and to her husband's. Judith shared that:

"Caring is a very tough job and as a carer you are given very little information and practical support. Society's expectations of carers are very high. Carers need to know enough to do the job. I needed to know as much information as my husband particularly about how this would affect our lives and to understand what was expected of me. I was virtually given no information and the information that was given to my husband was off poor quality. The main information focused on him (quite rightly) but I felt on the periphery. As a carer all my focus was on other people and I neglected to look after myself."

Thank you Judith for setting the scene, sharing a very personal experience and for setting the context for the workshop so well!!

These sessions were followed by participants contributing to a round table discussion where each participant was allocated into a working group that included patients, carers and professionals. The discussions focussed on:

- How do carers information needs differ to patients?
- How do you think information prescription could work for carers?
- What should they include?
- Who should give out carers information prescriptions
- Are there any problems or issues that you foresee with Information Prescriptions for carers?

Each discussion group was facilitated and facilitators were asked to feedback the main messages from the discussion.

The key themes that emerged were:

How do carers needs differ?



- Carers often need information that is more practical
- Carers information is not necessarily different but needs to be given in a different way for example at differing times and more practically focused i.e. what does this mean for our lives?
- Carers require information on what impact cancer will have on the person they are caring for both physical and psychologically
- There needs to be an acknowledgement and realisation of the effects of 'caring' on carers
- Consideration needs to be taken of the fact that there may be multiple carers
- Carers information needs may be come greater than the patient's information needs as the journey progresses
- Carers require support and sign posting both for themselves and for family members in dealing with bereavement.

What should a carer's IP include?

- Carers often need signposts to where to get good quality reliable information
- Carers want information about what impact cancer will have on relationships
- Carers are often looking for information that will signpost them to where they can get family support
- Signposting or information on finance and family benefits was identified as important
- There was a clear message that often there is an assumption that carers know how to 'care'. Signposting to information that will provide guidance on caring would be very helpful
- The IP should include practical support broken down into
 - Social
 - Physical
 - Spiritual
 - Psychological

Who should issue carers IPs?

A range of professionals who could give carers IPs out were identified including:

- CNSs
- Cancer Information Centres
- Surgery specialist nurses
- Information Mangers
- Pastoral care



In general there was a view that although the CNSs were very supportive of carers may be they were not the right people to provide the carer's IP and that their role would be to signpost carers to other professionals who would provide the IP to the carer.

Another consistent view was that there is no hard and fast rule as to who should issue the carers IP. It should be personal to each individual and issued at the right time for them.

What problems or issues do you foresee with the implementation of information prescriptions?

Confidentiality was a theme that emerged and there was a view that this could be best managed if it was not the CNS who was issuing the carer IP.

One of the key questions asked was when does a relative or friend or partner becomes a carer?

The Afternoon

The afternoon session was designed to give participants some focused time to explore:

- What should the carer's information prescription look like and contain?
- When and where should carers information prescriptions be issued and by whom?

Participants worked in small groups of patients, carers and professionals with a facilitator. Feedback from the sessions is outlined below.

What should the carer's information prescription look like and contain?

Feedback from the carers group included:

- Important to be clear who the carer is and it may be that there are a number of carers
- The carer's IP should be aimed at the personal carer and not professional carers
- General there was agreement with the headings on current IP form however the details do need changing
- Would like to see a list of information of what carers need to do on a daily basis
- Re-write the pathway – a carers focused pathway
- Signposting section needs re-writing to focus on carers needs
- Given out at the same time as the patients IP

Feedback from the patient group included:

- There needs to be an identified carer
- Should contain an emergency helpline number Out of Hours, NHS Direct etc.

Feedback from the professional group included:

- Carer's IP could be an add on sheet to the Patients IP – could be left in tact or torn off and given to a carer – give carer only what they want them to have
- There needs to be different websites and signposting
- Information needs will change throughout the pathway
- Add in Key worker contact details
- Explanation to be given to the carer about the IP
- Issued – by CNS/Key Worker who issues patients IP



A general discussion was then held about the idea of the carer's IP being integrated within the patients IP – for example a tear off strip. Generally there was a view that the carer's IP needs to be separate.

A further general comment was that it is helpful to have a checklist of information so that carers know what is available to them – otherwise they do not know what they don't know!

When and where should carers information prescriptions be issued and by whom?

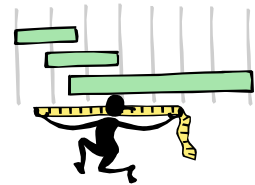
Feedback from the groups in response to this area was:

- Someone in a GP practice or pastoral care could issue the IP
- Information Managers in the Information Centres
- CNS/Key workers – although it was felt that they had prime responsibility of the patient and maybe they should sign post the carer to a different resource who could issue the carer's IP
- The time of issue will need to be individual

Feedback and Evaluation

The day was evaluated through immediate feedback from participants on:

- What was good about the day?
- What could have been better?



Formal evaluation forms were also distributed. A copy of the evaluation report can be accessed via either Elaine or Sheila.

And Finally

Having reviewed all the materials from the day we believe **eight key messages** (The A to G of Carers IPs) have emerged that will guide and drive the development of project. These are:

1. **A** carer's Information Prescription is a good idea
2. **B**oth patients and carers information needs must be catered for
3. **C**arers information needs are different to patients information needs
4. **D**o not assume that carer know 'how to care'
5. **E**very carer wants help to know what they 'don't know'
6. **F**urthermore, there is a need to develop a carer's information pathway
7. **G**enerally the same but different! - A carer's IP needs to include some of the same information as in the patients IP but it also needs to include some different information and signposts.
8. **H**ighlight that a carer's IP is separate to the patients IP