

Trust Board Meeting: 11 September 2013

TB2013.98

Title	Patient Story for Trust Board
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Status	For information
History	Patient stories are regularly presented to Trust Board and Quality Committee.

Board Lead(s)	Ms Liz Wright, Acting Chief Nurse			
Key purpose	Strategy	Assurance	Policy	Performance

Executive Summary

1	This story outlines some of the issues faced by men who have prostate cancer, and their treatment.
2	This story highlights the key issues related to the lack of appropriate and timely information to provide patients like George with the level of knowledge to support decision making about treatment options and the implications. The clinical team, led by senior medical and nursing staff recognised this need based on feedback, discussion and focus groups with patients. This led to the initiation, together with key clinical staff, of the establishment of the Oxford Prostate Cancer Support Group (OPCSG), in order to provide this peer sharing of coping mechanisms and support. This has been a successful partnership between the clinical team and patients.
3	OPCSG now provides vital emotional and practical support to men through their patient peers, who are experiencing the same devastating life changing issues along with their families. It has helped them and their family come to terms with their illness, feel more positive about their own health outcomes and quality of their life.
4	The wider learning from this story is that other patients receiving services in the Trust may benefit from a similar groups supported by 'Patient Leaders'. This recommendation will be taken forward through the Patient Experience Strategy (due to go to TME on the 12 th September 2013) within the patient leadership programme.

Introduction

1. This story by the Oxford Prostate Cancer Support Group (OPCSG) is being presented to the Trust Board with regard to highlighting the key issues related to appropriate and timely support, information; and particularly understanding the importance of patient participation, partnership and leadership in their own health care.
2. The patient's own story can be found in Appendix 1.

Rationale for selection

3. This story was selected as part of the series of patient story presentations to the Trust Board and Quality Committee, highlighting key issues of learning.
4. This story demonstrates the importance of peer support and patients as leaders.

“NHS organisations can use patient leaders in a wide range of roles, on patient reference and participation groups, as peer supporters, health champions, foundation trust governors, or as experts by experience. They can help boards, managers and staff to understand the patient experience, improve collaboration, support other patients and families, and hold services to account.”

Kings Fund, *Leadership by Patients*, 2013¹

Key issues highlighted and actions

5. Prior to OPCS, the medical and nursing staff offered written and verbal information and advice on treatment options, to patients diagnosed with prostate cancer. Patients found it difficult to make a decision about their treatment based on this information as it lacked detail and wider understanding. More importantly there was a gap identified related to support from people who can understand the experience, which can be devastating to an individual and their families. Patients who have used the support group have commented on the importance of talking through treatment options with someone who has had the same experience and understands the emotional and physical implications.
6. This reinforces issues raised in the previous patient story presented at the Quality Committee in August regarding the importance of peer support and information from those who have had direct experience. This enables patients to feel more empowered and in control of their choices and treatments.
7. The support group also provides vital emotional support to patients and their families throughout their treatment, both face-to-face and via a helpline.
8. This story highlights the need to explore the possibilities of patient peer support structures being utilised in other clinical areas of the trust. This links with the 'Patient Leadership Programme' which forms part of the Patient Experience Strategy (which will be discussed at TME on the 12th September 2013).

¹ Accessed 3rd September 2013 from: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/patient-centred-leadership-rediscovering-our-purpose-may13.pdf, page 25.

9. The OPCSG run information stalls at open days which encourage men to health screen for prostate cancer through having a PSA test². Feedback from men has demonstrated that this has been effective way of detecting prostate cancer early.

Conclusion

10. The OPCSG is an important practical and emotional resource for patients with prostate cancer and their families which works in tandem with the senior medical and nursing clinical staff.
11. The group is an example of patient leadership and the role in patient and family support and service transformation.
12. The contribution that this support group provides is highly regarded by the clinical team who work in partnership with OPCSG.

Next steps

13. The Trust will enable wider learning for clinical staff to consider similar patient led support groups to work in conjunction with clinical teams
14. The Trust is aiming to become a member of the Patients Association in order to facilitate inclusive workshops for clinical teams and patients who want to develop similar support groups.

Recommendation

15. The Trust Board is asked to note the patient story and the actions being taken.

Liz Wright

Acting Chief Nurse

Paper prepared by:

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Patient Experience and Involvement Manager

August 2013

² PSA test: tests for levels of PSA in the blood (PSA levels can range from 1ng/ml to hundreds of ng/ml and levels are considered raised if over 3ng/ml for men above 50 years; 4ng/ml for men above 60 years; and 5ng/ml for men above 70 years).

Appendix 1: Patient Story

George's Story

Background

George is the secretary of the Oxford Prostate Cancer Support Group. George's father died and was found to have had prostate cancer when he died. George's brother had his prostate removed seven years ago following a Prostate-Specific Antigen (PSA) test, which was part of another examination.

George's brother advised him to have an annual PSA test, and he was reluctant at first but went along. The first couple of tests were normal, but the third suggested further tests were needed.

Diagnosis

George went for a biopsy, and the results showed he had prostate cancer. Urology/Oncology Clinical Nurse Specialist Rose Southby delivered the news, and the treatment options were explained to George: surgery, radiotherapy, medication or do nothing.

A difficult decision

He went away with a series of documents to support the verbal information he had been given, but felt he was on his own and it was difficult to make a decision on which course of treatment to take. The doctors and nurses provide information on each course of treatment to take and the likely outcomes.

"I felt I hadn't a clue on how to make the decision, but I was lucky because both my daughters and my son-in-law are doctors, so they gave me advice. I decided I wanted surgery but I was advised that as I was over 70, this would not be possible. I pushed for surgery as I decided this was my best treatment option, so I had a radical prostatectomy."

Support before and after surgery

George was in hospital for three days then sent home and told to come back in two weeks. After this he went home again was told to come back in three months' time for a PSA test. George felt he had good advice from his family and was capable of handling the experience, but was not sure how others would have managed.

Patient feedback

A year after George's operation, the Urology department at the Churchill wrote to patients asking for their suggestions to improve the experience they had received. Other men had had similar experiences to George, where they had felt that the advice from the doctor and nurse had not been sufficient to aid decision making: the health care professionals could give information based on fact, but could not draw on personal experience. As a result of this, a peer support group was suggested.

The department arranged a meeting, and a speaker from the Chilterns Prostate Cancer Support Group came to talk about their support group.

Forming the support group

In March 2010, a meeting was called and four people put themselves forward for the posts of chairman, vice chairman, secretary and treasurer for the Oxfordshire Prostate Cancer Support Group. At first, 23 men joined the group. This has now risen to 143. The group is funded entirely by charitable donations and committee members do not receive any income.

The support group's function

The group does not offer advice about treatment options, but is able to give information based on personal experience and gives men and their families the opportunity to speak to someone who understands in confidence. George runs the OPCSG support helpline to offer support to men who have been newly diagnosed or are going through treatment, as well as their relatives.

“One of the most useful functions of the support group is to talk through treatment options which have been offered with someone who has been through the same treatment – it takes away the vagueness of it. Doctors and nurses can advise as they have seen people go through the treatment, but they have never actually experienced it themselves. Even the Prostate Cancer UK helpline is run by nurses.”

The support group meetings also provide a valuable forum for men to share experiences and support each other.

“Our group meets on average every 6 week, where we have either a speaker on a medical subject or a social event. This gives our members the opportunity to make friends, and talk to each other about their experiences, doubts and fears. These meetings are always very successful – 40 to 50 people turn up and there is always positive feedback at the end or following the meeting.”

OPCSG also run information stalls at several events, which acts as a first point of contact with the support group and as a means of raising awareness in the community.

“We encourage men to have a PSA test. Sometimes they come back the next year and tell us they went and it was all fine, or sometimes they come back and thank us because it turned out they did have cancer and managed to catch it really early.”

All men diagnosed with prostate cancer at OUH are now given a blue information folder with the OPCSG details. Positive feedback from people who have used the group demonstrates how vital it is for patients to express and discuss their experiences, and how they have been able to support patients through their decision making and life choices with their families.

Appendix 2: Email from Clinical Nurse Specialist Rose Southby

Dear George, please pass on this comment from me:

I hope you don't mind if I take this opportunity to say a few words, I am a Urology/Oncology Clinical Nurse Specialist and I would like to say how invaluable the OPCSG has been over the last few years.

All newly diagnosed patients are given the details of the support group and I know for many that the group provide much needed support at a very difficult time. The group are able to share their own personal experiences with the newly diagnosed patients and can indeed give 'hope' to some patients that may be feeling a little bit morbid about the situation as they can clearly see that our members have been treated for prostate cancer and are continuing to enjoy life.

After treatment the group provides continuing support & education for its members through group meetings, newsletters, website and emails. It is a group that has open communication with the relevant clinicians and works alongside the OUH NHS Trust and other charities in caring for the patients with prostate cancer.

I would like to say a big thank you on behalf of the OUH NHS Trust

Rose Southby
Urology/Oncology Clinical Nurse Specialist

Appendix 3: Action plan

Action	Progress
<p>Encourage other services in the trusts to set up peer support systems. This forms part of the Patient Leadership Programme in the Patient Experience Strategy.</p> <p>Peer support systems to consider:</p> <ul style="list-style-type: none">• Emotional support to newly diagnosed patients and their families and those undergoing treatment or coming to terms with changes.• Patients as advocates for health checks or healthier lifestyles.	<p>Funding for patients association membership has been sought.</p>