Improving support information with an integrated CNS service

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**ABSTRACT** Sweeney, E., Tapper, Y. (2006) Improving support information with an integrated CNS service. *Nursing Times;* 102: 17, 28–30. Clinical outcomes guidance highlights that a clinical nurse specialist is a necessary member of the multidisciplinary team within gynaecological oncology. Two clinical nurse specialist posts in gynaecological oncology have been developed within the North London Cancer Network. This article discusses the importance of these roles and includes results of a patient satisfaction survey.

Gynaecological malignancies account for approximately 20% of cancers in women (Richard-Smith and Barron, 1999). The Calman-Hine report (Department of Health, 1995) and clinical guidelines on improving outcomes for gynaecological cancers (NHS Executive, 1998) suggest a structure for multispecialist cancer services. The guidelines aim to ensure women diagnosed with a gynaecological malignancy receive specialist treatment, and recognise that a clinical nurse specialist (CNS) is a necessary core member of the multispecialist team.

University College London Hospitals (UCLH) Foundation Trust was designated a gynaecological cancer centre in April 2002. The North London Cancer Network (NLNCN) comprises cancer units and a specialist cancer centre, the units being:

- Barnet and Chase Farm;
- Royal Free;
- Whittington;
- North Middlesex;
- Princess Alexandra (Harlow) Hospitals.

**Clinical nurse specialists**

Access to a CNS enables women and their families to spend as much time as they need discussing issues related to their disease and enables women to feel comfortable asking questions about their condition. Patients appear to derive great satisfaction from this special relationship (McCreddie, 2001). Clinical nurse specialists are usually present with women and their families/carers when cancer is diagnosed and spend time with them to give emotional support. They can provide information on various issues including cancer treatments, menopausal symptoms, fertility advice and benefits. This can assist in the decision-making process about treatment options.

The NICE (2004) **Supportive and Palliative Care Guidelines** recommend that people with cancer should receive detailed information about their condition, and the treatments and services available. They also recommend that mechanisms be developed within a multidisciplinary team to promote continuity of care, which should include the nomination of a person to take on the role of the ‘key worker’ for individuals; this is usually the CNS.

A cancer diagnosis is distressing and can be difficult to accept. It can also compromise patients’ ability to assimilate further information (Tait, 1991; Rose, 1994). Women who have access to a CNS can be directed to support and information that meets their individual needs at an appropriate time.

The US National Cancer Institute (edwards et al, 2005) points out that people with the same cancer diagnosis can experience very different levels of distress, and healthcare professionals cannot predict how an individual will cope with cancer. It is therefore important to recognise the specific factors that influence coping strategies. This is a key challenge as women may need varying levels of information at different times through the course of their disease. As the point of contact for patients and their families/carers, the CNS can provide this information and support as and when required.

**Developing the role**

The North London Cancer Network has developed the role of gynaecological oncology clinical nurse specialists working between a cancer unit and the cancer centre. This followed the report of the 2001 Cancer Peer Review Process, which identified the need for specialist nurses.

The first ‘training’ CNS role was established in May 2003 and works between the Royal Free Hampstead NHS Trust and UCLH NHS Trust. The second CNS commenced in June 2004, between Barnet and Chase Farm Hospitals NHS Trust and UCLH.

The role includes attending oncology and rapid-access clinics and seeing any women with suspected cancers, returning for results or with recurrent disease. These visits offer an opportunity to discuss...
current issues with women, such as a cancer diagnosis and its treatments, and to provide information and support on a range of issues. Women facing recurrent disease may have significant survivorship issues due to the extent of their disease and McCorkle (2003) points out that this can often lead to feelings of uncertainty, isolation and distress.

For these women being linked in to the CNS service provides access to information about second-line and third-line treatments and coping mechanisms. It also enables a smooth transition between the cancer unit and specialist centre. Seeing women in the cancer unit enables us to offer this information and become a point of contact prior to referral to the specialist centre or elsewhere if they are treated locally. Clinical nurse specialists also act as a focus for patients in the cancer unit and specialist centre multidisciplinary team meetings and often act as patients’ advocates.

The number of referrals from hospitals classified in north London to the UCLH cancer centre can be seen in Tables 1–2. There are currently no figures from Princess Alexandra Hospital in Harlow, which joined the network in 2005.

The two CNS roles within the network have involved developing, enhancing and assisting in the patient’s pathway by ensuring women with a gynaecological malignancy have a point of contact and support for themselves, their families and carers. Macmillan Cancer Relief has adopted the two posts. Women are often seen in a clinic or admitted to their local hospital and it is at the point when a gynaecological cancer is suspected that they and their families and carers need specialist support, information and advice about the potential diagnosis, treatments and beyond.

The CNS role is also a focus of communication between the patient and their specialist team. The CNS may act as the patient’s advocate and because of this aspect of the role, an evaluation of patient views of the service was undertaken.

### Service evaluation

A patient survey was carried out in 2005 to find out what patients thought of the gynaecological oncology service. The women chosen to be invited to participate in the survey were patients between January 2004 and December 2004.

A postal questionnaire was distributed to 20 women who had received their treatment at the cancer unit or had been referred to the specialist centre. Out of the 20 questionnaires sent out, 13 replies were received – a response rate of 65%. The women ranged from 53 to 78 years of age.

### Results

Of the 13 participants:
- 11 patients were given information at diagnosis;
- 11 knew how to contact the CNS;
- Six patients contacted the CNS, by telephone, after diagnosis to go through the diagnosis or to ask further questions;
- 10 patients who were referred to the specialist centre felt that they understood why they had been referred and had received enough information about the specialist centre.

One of the issues raised was travelling time and this has been a subject for discussion in the past. The patients from this survey were travelling on average between half-an-hour and an hour to the specialist centre. One patient spent one-and-a-half hours travelling but felt that this was acceptable.

Generally all respondents felt that the quality of service was good including:
- the information provision;
- the length of time of the consultation;
- the environment.

In addition participants commented on the ability to contact the CNS if questions arose following the initial consultation.

In the open comments section of the survey a number of patients said that they wanted to maintain contact after treatment. This was regarding life-adjusting issues after a cancer diagnosis and

### TABLE 1. NEW CANCERS AND CANCER RECURRENCES TREATED AT SPECIALIST CENTRE

<table>
<thead>
<tr>
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<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
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<tbody>
<tr>
<td>Ovary</td>
<td>23</td>
<td>101</td>
<td>117</td>
<td>105</td>
</tr>
<tr>
<td>Endometrium</td>
<td>19</td>
<td>34</td>
<td>90</td>
<td>64</td>
</tr>
<tr>
<td>Cervix</td>
<td>11</td>
<td>49</td>
<td>41</td>
<td>39</td>
</tr>
<tr>
<td>Vulva</td>
<td>7</td>
<td>18</td>
<td>17</td>
<td>8</td>
</tr>
<tr>
<td>Vagina</td>
<td>-</td>
<td>5</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>5</td>
<td>17</td>
<td>6</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>-</td>
<td>-</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>60</td>
<td>212</td>
<td>295</td>
<td>233</td>
</tr>
<tr>
<td>Recurrences</td>
<td>13</td>
<td>14</td>
<td>38</td>
<td>26</td>
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</tbody>
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This article has been double-blind peer-reviewed.

For related articles on this subject and links to relevant websites see www.nursingtimes.net
range from emotional issues to family and sexual issues. It is interesting to note that even though these patients were at least a year out of treatment, these issues still remained important to them. Many participants stated that they felt that the CNS was the most consistent person during their journey and this concords with the findings of Barker and Turner (1994).

Working between the cancer unit and specialist centre meant that the CNS had been present at diagnosis and would also be present at the specialist centre where patients would continue treatment. It is generally recognised that if patients are well supported, psychological adjustment and coping is much improved (Borwell, 1996; Tait, 1991).

The benefits

It is now two-and-a-half years since both roles were established within the network. During this time there has been a significant change in practice at the units and specialist centres in terms of management of patients and referrals. There is a consistent clinical nurse specialist to ensure the smooth running of the patient pathway in terms of information and support provision. This includes the transition of patients from unit to specialist centre. And this is then reflected in reduced waiting times for treatments.

Information regarding the system at UCLH can also be conveyed so that women and their families/carers can anticipate what to expect from a referral to the specialist centre. This assists the effectiveness of the patient’s pathway and, by providing a point of contact, it helps to reduce the anxieties experienced by women and their families/carers.

Clinical nurse specialists provide essential links to local services such as cancer support groups and community palliative care. It is beneficial for patients and their families/carers if they maintain links with local groups to ensure access to the best services.

The network continues to develop and establish local nurse-led clinics. There are two nurse-led clinics, one at UCLH and one at Chase Farm Hospital. This service provides face-to-face/one-to-one support, information and/or advice to women who live locally. It also allows women to discuss specific issues or concerns prior to the commencement of treatment for a gynaecological malignancy.

The difficulties

Developing the clinical nurse specialist role has not been without its challenges. There can be problems in establishing recognition of the clinical nurse specialist posts at cancer units where this is a new service. It has taken a significant period of time to develop effective working over two or three sites but this improves over time.

Definition of office space or facilities at units has also been challenging. Access to a telephone and computer at all sites allows effective communication with patients, their families/carers and other healthcare professionals. There is a centralised telephone number for all patients to ensure patients’ telephone calls and messages are received and answered within a satisfactory time period.

It is important for a clinical nurse specialist to be able to clarify effective communication with consultants, all members of the core and extended multidisciplinary team, as well as other healthcare professionals. This can be time-consuming.

The future

In conclusion, clinical nurse specialists working at a centre unit and a cancer centre have an important role in becoming a point of contact for patients with a suspected or diagnosed gynaecological malignancy. They can provide information and support to women, and their families/carers at diagnosis and continue this process throughout their treatment and beyond. The team is also looking to expand unit centre working for other units across the network where they currently do not have a clinical nurse specialist. The main difficulty in this instance is funding, which is not always easy to find. However, by being able to demonstrate the benefits of a clinical nurse specialist working within a unit and specialist centre, applying for the funding of new posts should be easier.