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CANCER SUPPORT

# CANCER CLINICAL NURSE SPECIALISTS

## What are they?

Clinical Nurse Specialists (CNSs) are dedicated to a particular area of nursing; caring for patients suffering from long-term conditions and diseases such as cancer.

Macmillan funds Cancer Clinical Nurse Specialists to support health care professionals in delivering effective, efficient services and to improve the quality of care for cancer patients.

*“The Macmillan nurses really helped me. They provided me with emotional support. There was a couple of times I felt a bit depressed, I spoke to a couple of nurses and they gave me a lot of advice and basically they listened.”*

This Impact Brief is part of a suite of Impact Briefs which provide evidence about the impact of Macmillan’s direct and indirect services, available at [www.macmillan.org.uk/impactbriefs](http://www.macmillan.org.uk/impactbriefs)

## Need



The number of people living with cancer will double to **four million** by 2030.<sup>6</sup>



The cancer journey is complex, involving care interventions by a range of different professionals. CNSs work with other professionals to provide and improve cancer care for patients.

## Reach



Macmillan helps to fund or support **4,323** nurse posts in cancer care (many of which are CNS).<sup>1</sup>

## Impact



Macmillan Nurses (many of which are CNS) helped and supported a total of over **554,896** patients in 2014.<sup>24</sup>



The average Macmillan nurse helped **158** cancer patients in 2014.<sup>24</sup>

<http://www.macmillan.org.uk/impactbriefs>

# CANCER CLINICAL NURSE SPECIALISTS

## INTRODUCTION

Macmillan helps to fund or support over 4,300 Clinical Nurse Specialist (CNS) posts in cancer care to support healthcare professionals in developing and delivering effective and efficient services and to improve quality of care for cancer patients.

CNSs are key workers, they treat and manage the health concerns of patients and work to promote health and wellbeing in the patients they care for. They use their skills and expertise in cancer care to provide physical and emotional support, coordinate care services and to inform and advise patients on clinical as well as practical issues, leading to positive patient outcomes.

CNSs also reduce treatment costs, increase efficiency, drive innovation and provide valuable information for service redesign as well as enable multidisciplinary care and communication between different teams.

## KEY FINDINGS

- **CNSs role in patients' cancer journey**

The cancer journey is complex and disjointed and involves the care interventions from various multi-site professionals such as oncologists, surgeons and counsellors. The CNS role provides and reinforces relevant information and appropriate liaison with other professionals and agencies to improve the cancer care process for patients.

CNSs improve quality and experience of care for patients, reinforce patient safety, demonstrate leadership and increase productivity and efficiency.

- **Variation in access to CNSs**

Access to CNSs varies both geographically and by tumour site, leading to inequalities in patient experience. On average there is only one lung cancer nurse in England for every 161 people diagnosed with lung cancer, compared to 117 people per breast cancer nurse.

- **Value for money**

CNSs represent good value for money. They reduce the number of emergency admissions, the length of hospital stay, the number of follow-up appointments, the number of medical consultations and provide support to enable people to be cared for and to die in their place of choice.

# DETAILED FINDINGS

## 1. What is the issue?

### i) Why are Clinical Nurse Specialists required by people living with cancer?

Each year just over 335,000 people are diagnosed with cancer in the UK.<sup>2, 3, 4, 5</sup> There are currently 2.5 million people living with cancer and it is estimated that this will double to four million people by 2030.<sup>6</sup> This rise is due to improvements in treatments, incidence increases and an ageing and growing population.<sup>7</sup>

The cancer journey is complex and disjointed and involves the care interventions from various multi-site professionals such as oncologists, surgeons and counsellors. Patients should have access to high quality, effective healthcare and CNSs have an important role to play in meeting their needs and expectations.

Research shows that current models of care are not identifying or meeting the needs of all patients living with cancer and that the current cancer workforce needs to adapt to improve care and support for cancer patients. The role of the key worker (one which a typical CNS would commonly hold) needs to become embedded in practice and the current and future workforce need to be developed with specific skills and specialist knowledge in cancer, for example understanding and supporting the management of consequences of cancer treatment.<sup>8</sup>

Further evidence highlights that the current system also faces challenges in expanding sufficiently to support the increasing number of cancer survivors. Improved survivorship services will have significant cost implications for the NHS and the wider economy and will require investment. Assessment and care planning, for example, requires CNSs time which may cost an estimated £15–20 million per year in England in staff time costs.<sup>9</sup>

#### **The role of Clinical Nurse Specialists**

The CNS role provides and reinforces relevant information and appropriate liaison with other professionals and agencies to improve the cancer care process for patients.<sup>10</sup>

#### **The main functions of the specialist nurse role can be described as:**

- technical
- information provision
- emotional support
- and coordination<sup>11</sup>.

*'Emotional support should be accessible to all patients, as psychological wellbeing is important when so much has to be faced.'*

*Often the psychological aspect of breast cancer is not considered a high priority by health professionals. Although this is understandable when their focus is on clinical issues, it should be an integral part of the overall care. The role of CNSs is crucial in this respect'*

***Mother and breast cancer survivor***<sup>12</sup>

**The high-level activities of CNSs can be separated into five main functions. In the context of cancer care these consist of:**

- Using and applying technical knowledge of cancer and treatment to oversee and coordinate services, personalise ‘the cancer pathway’ for individual patients and to meet the complex information and support needs of patients and their families.
- Acting as the key accessible professional for the multidisciplinary team.
- Undertaking proactive case management and using clinical acumen to reduce the risk to patients from disease or treatments.
- Using empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines as appropriate.
- Using technical knowledge and insight from patient experience to lead service redesign, to implement improvements and make services responsive to patient need.<sup>13</sup>

Evidence shows that CNSs can save resources leading to greater efficiency and better outcomes. CNSs identify the specific physical and emotional needs of people and co-ordinate different parts of system to work together to address those needs and help provide care closer to home. CNSs work across different teams and their experience is often invaluable to senior management as they can advise on the specificities of service provision to inform service redesign.<sup>14</sup>

In 2013 74% of patients with a CNS said they were given easy to understand written information about the type of cancer they had, compared to 49% without. 74% of those with access to a CNS agreed that they had been involved in their treatment as much as they wanted to be, compared to only 57% of those that did not have a CNS; and 54% would have liked more financial information and advice but did not receive it.<sup>15,16</sup>

**ii) Why are there inconsistencies in access to Clinical Nurse Specialists?**

Access to cancer CNSs varies both geographically and by tumour site, leading to inequalities in patient experience<sup>17, 18, 19</sup> On average, there is only one lung cancer nurse in England for every 161 people diagnosed with lung cancer, compared to 117 people per breast cancer nurse. A 2013 survey by the UK Lung Cancer Coalition found that almost a quarter (22%) of lung cancer patients surveyed had not received continuous support from a CNS or key worker.<sup>20</sup>

**Working environment**

A 2008 Royal College of Nursing (RCN) survey revealed the scale of the potential loss of CNS expertise. More than a third of CNSs said their organisations had a vacancy freeze in place, almost half reporting being at risk of being downgraded and 68% had to see more patients. The survey also revealed that 1 in 4 specialist nurses were at risk from redundancy and 45% were asked to work outside their specialty to cover staff shortages.<sup>21</sup> In the current challenging financial climate there is a real danger of care providers reducing staffing to achieve short-term savings, without consideration of the risk to patient care and to longer-term cost implications.<sup>22</sup>

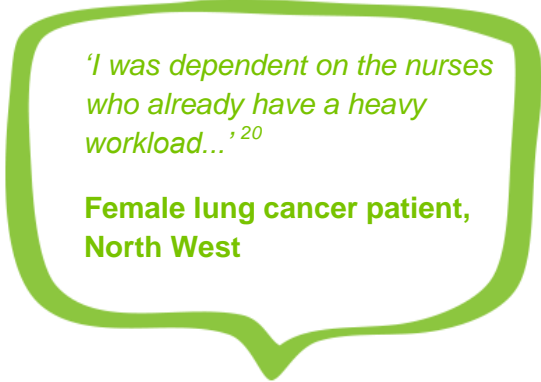
**Insufficient increase in posts**

Although there has been a small increase in CNS posts since 2007 in brain/central nervous system, lung, upper gastrointestinal and haematological cancers, the increase is insufficient to keep pace with the current growth in cancer prevalence.<sup>35</sup>



*'I understand that the nurses are under pressure but we would have liked more honesty and counselling support.'*<sup>20</sup>

**Lung cancer carer,  
South West**



*'I was dependent on the nurses who already have a heavy workload...'*<sup>20</sup>

**Female lung cancer patient,  
North West**

## Challenges preventing quality care provision

A 2007 survey of breast care nurses found that almost 50% of nurses felt unable to provide the quality of care to all breast cancer patients that they would like to. This was due to a variety of reasons including increased workload because of new, additional duties, staff shortages, and redeployment to other areas, e.g. general wards.<sup>23</sup> This example shows that there is a high demand for specialist nurses.

There is also inconsistency in job titles of roles that can be categorised as a CNS. Recent research found that almost 50 different job titles are in use for nurse specialists working in the field of urological cancers. Inconsistency in job titles has also been related to ambiguity in terms of the requirements and duties of the CNS role.<sup>22</sup> A recent HSJ supplement favoured the title of 'specialist nurse in advanced practice'<sup>14</sup> for these types of roles.

In addition, the specific services offered by CNSs may vary across the cancer care pathway as there is no minimum standard for the skills and knowledge required to function in a nurse specialist role.

## 2. What is Macmillan doing to address the issue?

In 2014, Macmillan had provided funding for or 'adopted' over 3,500 nurse posts. The nurses in these posts in 2014 helped over 554,000 cancer patients.<sup>24</sup> In addition to these patients, our Macmillan Nurses helped many more carers, family members and friends. The average Macmillan Nurse helped 158 cancer patients across the whole year in 2014.<sup>24</sup>

Macmillan supports the position of CNSs in cancer care by 'pump-prime' funding. Macmillan typically funds the posts for 3 years or less before the partner organisation continues supporting the role. These CNSs are often referred to as 'Macmillan nurses' and retain this title when charitable funding ends.

Macmillan nurses are registered nurses, who have been educated to first degree level and have completed post graduate learning or who are working towards post graduate qualifications. They are clinical experts within a specialist field such as young people, palliative care or specific cancer types.<sup>16</sup>

The Macmillan CNS provides leadership, innovation and expertise, directly, when patients have highly complex care needs that require specialist assessment and care planning, or indirectly, by supporting and guiding others to provide care and support.<sup>25</sup>

Macmillan supports the introduction of CNS posts for people with cancer to develop a structured, supportive service for people and their families.

### The objectives of the Macmillan CNS are to:<sup>10</sup>

- support healthcare professionals
- develop needs-based education and training for staff
- standardise and develop patient information
- empower patients to be proactive in their own care
- deliver relevant health promotion messages to patients and the public.

One to one CNS care is central to the patient-focused 'no decision about me without me' principle set by the Department of Health.<sup>43</sup> Macmillan is working in partnership with the Department of Health and equivalent in Scotland, Wales and Northern Ireland, to develop and improve the current cancer CNS workforce, to make the role more fit for purpose in today's health environment and increase cancer CNS skills. Part of this work has been to produce a report to support clinical teams, commissioners and providers to understand and evaluate the contribution of CNSs in cancer as they plan their local workforce and service improvement strategies. The report can be found on the

external Macmillan website. Macmillan has also contributed to an economic analysis of providing the required number of CNSs to meet the needs of all cancer patients. The results show significant potential savings for the NHS if workforce gaps are filled.<sup>26</sup>

### 3. What is the impact of CNSs?

CNSs across the country are already transforming patients' experiences of cancer care. Below is an overview of the impact a CNS has<sup>13</sup>:

#### Improving quality and experience of care.

- Managing complex, individual and changing information and support needs of patients and carers.
- Supporting patients in choices around treatment and care.
- Enhancing recovery and delivering care flexibility and closer to home.
- Facilitating set up of support groups

#### Reinforcing Safety

- Delivering safe, nurse-led services.
- Identifying and taking action to reduce risks.
- Facilitating rapid re-entry into acute services, if appropriate.

#### Impact of key CNS led activity

#### Increasing productivity and efficiency

- Intervening to manage treatment side effects and/or symptom control, preventing unplanned admissions
- Providing nurse-led services that free up consultant resource.
- Empowering patients to self-manage their condition.

#### Demonstrating leadership

- Educating the wider healthcare team and acting as a mentor.
- Identifying and implementing service improvement and efficiencies.
- Determining measurable outcomes, auditing practice, and sharing good practice and innovation.

## i) Improving quality and experience of care

The English government's cancer reform strategy highlights that patients regularly emphasise the role of the CNS in improving their cancer experience.<sup>27</sup>

Access to a CNS has been shown to play a vital role in delivering high quality, patient-centred care and treatment to people with cancer. Patients allocated a CNS have been shown to be more positive about the experience of their care. This could be because patients supported by a CNS receive holistic care that includes emotional and practical support as well as addressing physical needs. Often patients can build closer bonds with their CNS and ask different kind of questions which they may not want to ask their doctor.<sup>14</sup> Access to a CNS has also been identified as increasing the chances of a patient receiving chemotherapy and helping to reduce emergency admissions and inpatient stays. Close connection with patients allows CNSs to ensure that new symptoms and potential diseases can be diagnosed earlier.<sup>14</sup>

The results of the 2014 National Cancer Patient Experience Survey support this. 89% of patients reported that they had been given the name of the CNS in charge of their care. Of these over 91% reported that the CNS had definitely listened carefully. Patients with a CNS responded far more positively than those without a CNS on a range of items related to information, choice and care.<sup>15</sup>

Recent research into complex treatment decisions for patients with advanced lung cancer showed that CNSs play a valuable role in supporting decision making and are seen as trusted sources of information.<sup>28</sup>


The National Lung Cancer Audit 2010 shows that in 2009 65% of patients seen by a lung CNS received cancer treatment compared to 30% of those who did not see a lung CNS. The audit collected data on more than 37,000 patients in the UK, representing approximately 95% of the expected number of new lung cancer cases.<sup>29</sup>

A UK survey of the experiences of men with prostate cancer found that specialist nurses were ranked the highest amongst healthcare professionals and help-lines, for the provision of emotional support around the time of diagnosis and treatment decision-making.<sup>30</sup> Macmillan nurses provide outcomes for patients that correspond to their emotional needs.<sup>31</sup>

Research has shown that significantly more patients who received nurse-led follow up from lung cancer CNSs died at home, which was their preferred location, rather than in a hospital or hospice: 40% compared to 23% receiving conventional medical follow up.<sup>32</sup> Additionally, in 2009 65% of people with lung cancer seen by a lung CNS received cancer treatment compared to 30% of those who did not see a lung CNS.<sup>33</sup>

A 2009 study of rheumatology clinical nurse specialists showed that almost a quarter of physical clinical interventions involved enhancing self-management principles and managing unresolved symptoms using specialist knowledge and assessment.<sup>34</sup>

CNSs provide holistic care by utilising and signposting to different service providers.



*'The Macmillan nurses not only provided me with psychological, spiritual and emotional help, but also practically and financially. When the going got tough, they were there for us in every aspect.'*<sup>35</sup>

**Cancer Patient**



*'Most specialist nurses in advanced practice, even if they're based in the acute sector, practise in the community. For instance, 30 per cent of a specialist nurse in advanced practice's work is generally done over the phone. So that's supporting patients in the community and supporting community practitioners of all types to manage increasingly complex care needs.'*

**Alison Leary, professor of healthcare modelling at London South Bank University**

Much of specialist nursing is primarily caring for patients who have long term conditions and who really need to be able to support their self care in the long term – which reduces the burden on all health services. Patients may be identified as not coping well can be referred to a self management programme and to other resources.

Although most CNSs in cancer are based in the acute sector, they may work with services in the in the community. This allows them to build partnerships between different healthcare professionals based in various settings. They can also

recommend patient referrals to the most appropriate services according to their specific needs because CNSs have a good understanding about what support is available and appropriate CNSs are known for their ability to facilitate multidisciplinary care between different healthcare organisations.<sup>14</sup>

## ii) Reinforcing safety

*'My Macmillan nurse has been there from day one. She's been a fantastic support. Any questions I have, to do with medication, symptoms or anything else, she's there.'*<sup>35</sup>

**Cancer Patient**

CNSs help improve patient experience and safety<sup>36</sup> because they have in-depth knowledge of the physical, psychological and social effects of a specific condition and play a key role in the management of patient care. They have considerable experience, are highly qualified and carry out a range of functions that make them a key member of a multi-disciplinary team (MDT).<sup>37</sup> A lot of CNSs have many years of experience in advance practice and they are equally familiar with technical aspects and case management.<sup>14</sup>

Patient safety and level of inadequate staffing are often interlinked. Between April 2008 and March 2009 more than 33,000 patient safety incidents were recorded as relating to the lack

of suitably trained or skilled staff.<sup>38</sup>

Cancer CNSs coordinate ward admissions for patients who are unwell, expedite outpatient clinic appointments, reorganise reviews to minimise cancelled procedures or operations and give advice on managing medication throughout the cancer journey. This enables patients to move through the system as smoothly as possible and diverts pressure away from other professionals such as doctors and the ward nursing team.<sup>39</sup>

A study in 2009 to monitor the complex workload of CNSs in rheumatology care revealed the importance of CNSs in providing safe advice on medication, showing that more than a quarter of physical clinical interventions involved management of medication including dealing with toxicity and rescue work associated with the unexpected adverse effects of treatments.<sup>27</sup>


### iii) Demonstrating leadership

A 2010 Department of Health report illustrates the ability for CNS roles to influence, lead and advance practice and demonstrates the extent to which advanced nursing practice can support positive patient outcomes.<sup>40</sup>

CNSs have a much greater role in the delivery of healthcare than they had five years ago. Between 2005 and 2010 the number of referrals to a specialist nurse clinic rose from 115,000 to 650,000; an average increase of approximately 107,000 a year. It is therefore evident that GPs and consultants are more likely now than ever to refer patients to specialist nurses.<sup>41,42</sup>

Cancer CNSs have clearly demonstrated their commitment to work collaboratively with their colleagues to ensure that patients have access to best practice, equity of care and continuity of care throughout the cancer journey.<sup>21</sup>

CNSs provide support to their colleagues and can be seen as experts by other members of the MDT, providing specialist advice and guidance to colleagues on a range of issues including symptom control and patient communication.<sup>22</sup> CNS expertise is essential to the functioning of MDTs and they are often nominated as the 'key worker' within the team.<sup>43</sup> They also have experience dealing with complex patients and clinical cases which equips them with good problem solving skills.<sup>14</sup>



*"The Macmillan nurses really helped me. They provided me with emotional support. There was a couple of times I felt a bit depressed, I spoke to a couple of nurse and they gave me a lot of advice and basically they listened."*

**Cancer Patient**<sup>35</sup>

### iv) Increasing productivity and efficiency

#### **Need for increased cancer support posts**

In 2010 The Department of Health commissioned Frontier Economics to conduct an economic analysis of the impact of providing enough posts for one to one support for all cancer patients in England. Frontier Economics estimated that around 1,200 new posts, a combination of specialists and support staff, are required to provide one to one care for all patients in England with cancer. The cost of this expansion in the workforce would be about £60m per year. Based on evidence that 12% of the associated workload is administrative rather than clinical, and assuming that this portion of the work could be handled by lower grade staff, the report indicates that the annual bill of £60m would be more than offset by savings of £89m per year.<sup>44</sup>

#### **Lowering admission rates**

CNSs ensure that patients are in hospitals only when they absolutely have to be there by providing appropriate advice and noticing any early symptoms of developing conditions. They can also help patients to self-help and manage their conditions reducing the need for additional stays in hospital.

By delegating administrative tasks and adopting a proactive management approach to patient care with the CNS as the key worker, a lung cancer nursing service in London has reported that the rate of lung cancer admissions for non-acute problems fell from 4 per month to 0.3 per month. Clinical nurse specialists who practise proactive case management and re-focus services in line with best practice therefore represent a good return on investment.<sup>45</sup>

#### **Value for money**

Many organisations have already noticed economic benefits of having CNSs. For the thousands of people across the UK living with long term conditions, including cancer, several studies have shown

that as a substitute for other health care professionals, including doctors, specialist nurses are both clinically and cost effective.<sup>21</sup> A study by the RCN found that outpatient work done by Rheumatology Nurse Specialists is worth on average each year £72,128 per nurse and saves £175,168 per nurse by freeing up consultant appointments. Telephone consultations also save £72,588 per nurse by reducing the number of GP appointments.<sup>27</sup>

CNSs represent good value for money, through reducing costs in primary care and saving consultants' time.<sup>27</sup> For example, recent research into delivery methods of follow up after colorectal cancer treatment found that telephone follow-up proved a viable alternative to hospital follow-up.<sup>46</sup> A number of functions performed by CNSs used to be performed by consultants but are now currently undertaken by CNSs.

CNSs experience of working in and with multi disciplinary teams means they can work to support different service providers in a range of settings: GPs, community nurses, district nurse teams.<sup>14</sup>

A survey conducted by the National Lung Cancer Nurses Forum and the UK Lung Cancer Coalition shows lung cancer nurses in England carry out more than a total of 71,000 hours of unpaid overtime every year – saving employing trusts nearly £1.5m per annum.<sup>47</sup>

An economic modelling analysis by Macmillan in 2009, focusing on the role of the CNS, suggested that service improvements along the cancer pathway could release about 10% of cancer expenditure in the Manchester area.<sup>48</sup> This related only to breast and lung patients admitted through the two week wait system in one health economy, however if extrapolated to a national level then the economic benefits could be significant.<sup>49</sup>

### **Cost of a Macmillan nurse<sup>50\*</sup>**

These amounts can fund a Macmillan nurse to help people living with cancer and their families receive essential medical, practical and emotional support.

Cost	CNS
1 Day	£204
1 Week	£1,020
1 Month	£4,418
1 Year	£53,021

\*For more detailed costs of these and other Macmillan services see [be.macmillan.org.uk](http://be.macmillan.org.uk) to download The Cost of Macmillan's Services fact sheet.

### **More effective and efficient treatments**

Management of serious side effects by CNSs can help to avoid chemotherapy dose reductions, delays and omissions and thereby improve the likely efficiency of treatment.<sup>35</sup>

A report by the RCN found that studies show benefits of specialist nursing roles include reducing referral times, length of hospital stays and the risks of post-surgery complications.<sup>10</sup>

Since 2005-06, there has been a 465% increase in outpatient attendances at specialist nurse clinics – a rise of more 100,000 outpatients a year.<sup>51</sup> Cancer CNSs hold follow-up clinics for cancer patients reducing the number of follow-up clinics and therefore increasing medical staff capacity to see new patients<sup>52</sup>. Evidence has shown that lung cancer patients receiving CNS led follow up had significantly fewer medical consultations with a hospital doctor in the three months following cancer treatment than conventional medical follow-up services.<sup>53</sup> This has also been demonstrated for breast cancer patients in several trials.<sup>54</sup> When specialist care via access to a Cancer CNS was compared to routine medical follow-up, results showed that point of need access can be provided by suitably trained specialist nurses and provides a fast, responsive management system at a time when patients really need it.<sup>55</sup>

## Case study – secondary breast cancer CNS benefits <sup>57</sup>

CNSs working in metastatic breast cancer prevent emergency admissions to hospital. They provide an alternative to unscheduled care by helping keep patients in the community. They do this by working with community teams and GPs to provide clinical solutions to complex problems. A total of 60% of the CNS's work is dealing with community-based issues. CNS prevent unscheduled care episodes approximately 26 times per year.

CNSs working with metastatic breast cancer patients reduce new to follow-up ratios in cancer units, releasing clinic and outpatient time for new patients. A CNS specialising in metastatic breast cancer will see an average of 13 follow-up patients per week in an outpatient setting. Matched against DH tariffs this represents £53,040 in income and the potential release of 13 slots to new patients (raising £159,120 per 48 week year). This means CNSs working with metastatic breast cancer patients can speed up pathways, help trusts meet targets, allow new patients to be seen and therefore generate more income.<sup>22</sup>

## CONCLUSION

The number of people living with cancer is expected to increase from 2 million to 4 million by 2030. Therefore, the number of people requiring specialist care and support will increase throughout the cancer pathway.

Cancer CNSs possess a wide variety of skills and expertise and use this knowledge to ensure that cancer patients experience the best possible care and support.

Cancer CNSs can help to improve quality of life for people with cancer through assisting with decision making, symptom management and emotional support. Cancer CNSs also help empower patients to self-manage their conditions leading to reduced costs for healthcare providers through hospital appointments, emergency admissions and consultant time. They take a holistic approach to treatment and they can also link up different health and social care services together.

Macmillan continues to fund and support cancer CNSs and urgently needs more charitable donations to keep these services supporting cancer patients and their families. Go to [www.macmillan.org.uk/donate](http://www.macmillan.org.uk/donate) or call 0300 1000 200 to make a donation.

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