Executive summary

Service impact reports: The Irish Cancer Society's (the Society's) service impact reports are a suite of reports developed to assess the impact of our services at 4 key stages of cancer support (preventive, supportive, survivorship, and palliative). The focus of this report is on our palliative service – Night Nursing.

Report aims: We hope to look at the difference our end-of-life Night Nursing Service makes to our service users. This is a vitally important step in ensuring we are delivering compassionate, supportive services of the highest possible standard. Examining the impact of the Night Nursing Service on the patients and families who have used it will help to determine the future direction of the service and ensure that the needs of its users are being adequately met.

Method: We engaged with our service users to hear their experiences first hand. A survey was given to 318 families and friends of individuals who used the service between 1st July 2015 and 31st of December 2015. We received a total of 137 responses. The survey questions were designed to measure 15 of the Society’s 26 service objectives.

Key findings: There is clear evidence from the responses that home is the preferred setting for end-of-life care. 84% of participants indicated that this was their loved one’s wish. There was a large sense of duty to facilitate this request; however, many felt ill-equipped to provide such intense care. One third of participants said that their loved ones would not have been able to die at home without a Night Nurse. Satisfaction rates were extremely high across 13 of the 15 objectives measured. The Night Nursing Service excelled in the areas of clinical care and emotional support. Signposting to other services and access were highlighted as areas for improvement. While respondents were overwhelmingly positive about the service, they felt that having access to it for a longer period of time would make it easier to cope, practically and emotionally, in a very stressful situation.

Conclusion: The Night Nursing Service is a crucial and necessary component of palliative care in this country. Overall satisfaction with the service is high. The service was shown to play a vital role in enabling patients to have a dignified death while providing emotional support to friends and families of the patient. Overall it makes a hugely positive impact on the lives of the people who use it.
"We can't put into words how much it meant to us. We will be forever grateful to have Mum home during her final days and that will stay with us forever.

Mam deserved the care and dignity she was afforded. The Night Nurse was an angel"

Daughter of a Night Nursing patient
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Chapter 1: Why we deliver services

Background

Unfortunately cancer is a disease that affects many families across Ireland. By 2020, 1 in 2 people will develop cancer during their lifetime.\(^1\) At the Irish Cancer Society we know that behind every statistic there is a person and we realise that being told “You have cancer” is life changing. We are determined to play our part, both in reducing the number of people who hear those words, and supporting people with a diagnosis in whatever way we can.

One of the key ways we try to do this is by providing services that make a real difference to people’s lives. This is at the heart of our work and is the basis of two of our strategic goals.\(^2\)

There are 4 key factors influencing the type of services we provide:

- **50% of cancer is preventable.** The good news is that people can reduce their likelihood of getting cancer by making certain lifestyle changes.\(^3\) However, a national survey found that the Irish public were largely unaware of cancer risk factors.\(^4\) This highlights a need to both raise awareness

\(^1\) Ahmad, Ormiston-Smith, and Sasieni, “Trends in the Lifetime Risk of Developing Cancer in Great Britain.”


\(^3\) Colditz, Wolin, and Gehlert, “Applying What We Know to Accelerate Cancer Prevention.”

\(^4\) Ryan et al., “Poor Awareness of Risk Factors for Cancer in Irish Adults.”
about the causes of cancer and to provide services that support people to live healthier lives. By educating people and supporting them to make positive changes we can help to reduce the number of new cancer cases each year.

- **Cancer incidence rates are increasing.** Each year there are around 37,000 new cancer cases, with this figure likely to rise to 40,000 by 2020.\(^5\)

Research has shown that people who receive a cancer diagnosis have a range of complex physical and psycho-social needs. Unfortunately, many feel there are not enough supports to help them cope with these challenges.\(^6\) Their diagnosis can also take a toll on the physical and emotional wellbeing of their friends and families.\(^7\)

As the number of people diagnosed with cancer increases, so does the need for services that provide information and support – for both the patient and those who support them.

- **People are surviving cancer for longer.** Latest figures show that 59% of men and 57% of women diagnosed with cancer currently survive for five years and longer.\(^8\) Unfortunately, while their physical health is improving, many cancer survivors report unmet psychological needs. In fact, studies have shown that these emotional needs are greater at the post-treatment stage than any other time, sometimes for years after a diagnosis.\(^9\)\(^10\) This demonstrates a need for emotional support services after treatment has ended.

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\(^5\) NCRI “Cancer in Ireland 2013 Annual Report

\(^6\) Sanson-Fisher et al., “The Unmet Supportive Care Needs of Patients with Cancer.”

\(^7\) Adler, Page, and Setting, The Psychosocial Needs of Cancer Patients.

\(^8\) NCRI, “Cancer in Ireland 1994-2013.”

\(^9\) Harris et al., “What Are the Unmet Supportive Care Needs of People with Cancer?”

\(^10\) ICS “Emotional Impact of Cancer Can Affect Cancer Survivors Years after Diagnosis.”
A quarter of deaths in Ireland each year are from cancer. With such a high number of deaths attributed to cancer, people need proper supports in place to help them to have a dignified death. Studies have shown that the home is the most popular setting for end-of-life care. Most people need support from friends and family for this to happen, and carers also have their own complex needs. Often those in support roles can have more unmet needs than the patient. This shows a need for a dedicated palliative service in the home, which supports the needs both of the patient and those who support them.

What services do we offer?

For the purpose of this report we have grouped our services into 4 key stages of the cancer journey.

Our services broken down into the four stages

11 Gomes and Higginson, “Home or Hospital?”
12 Soothill et al., “The Universal, Situational, and Personal Needs of Cancer Patients and Their Main Carers.”
At the **preventive stage** we aim to educate and support people who are concerned about cancer and want to reduce their risk. We do this through programmes that support smoking cessation (**We Can Quit** and **X-HALE**), and promote wellbeing and health literacy (**Fit for Work and Life**), and through our free **publications** and our **website** information.

At the **supportive stage** we provide practical and emotional support for people who have recently been given a cancer diagnosis and their friends and families. We do this by providing confidential advice through our **Cancer Nurseline** and **Daffodil Centres**, arranging transport for chemotherapy patients (**Volunteer Driver Service**), administering a travel fund (**Travel2Care**) and our free **publications** and our **website** information.

At the **survivorship stage** we hold an annual national conference (**Living Well with Cancer**). We facilitate peer support by connecting people with a recent diagnosis to someone who has lived through that experience (**Survivor Support**). We also fund peer-to-peer educational and wellbeing programmes in affiliated cancer support centres. (**Living Life, Strides for Life, Prostate cancer psycho educative programme**), as well as funding **counselling** for survivors.

At the **palliative stage** we provide end-of-life support for patients and emotional and practical support for their friends and families. We do this through the provision of a home nursing service (**Night Nursing**).

As the focus of this report is on our palliative service, we will take a more in-depth look at these services in the next chapter.
Chapter 2: Our palliative service

Night Nursing

Introduction: The Night Nursing Service began in 1986. The service enables patients with cancer and other incurable illnesses to die at home, surrounded by their family and friends. It is the only service of its kind in Ireland, it is free to use and completely funded by donations. There are currently 200 night nurses employed by the Society to provide this care around the country.

How the service works: If someone wants to use the service, the health professional who is looking after their loved one needs to book on their behalf. Once a night of care is requested, the Society arranges for a Night Nurse to visit the patient's home. The nurse monitors the patient and provides pain relief for up to 10 nights of care.

Why there is a need for the service: Public surveys have shown that two out of three people would prefer to die at home. People dying in institutions like hospitals or hospices have more unmet needs in terms of pain relief, communication with the medical team, emotional support, and dignified treatment than those who die at home. Caregivers also tend to prefer the home setting, as there is a perception that hospital staff are too busy to provide adequate care. Relatives of people who received care at home were also more likely to report a favourable dying experience, when compared with institutional settings. This supports our own evaluation of the service, which found that 95% of family respondents were very satisfied with their interactions with the Night Nurse, and the presence of a Night Nurse provided comfort for the patient.

14 Pollock, “Is Home Always the Best and Preferred Place of Death?”
15 Teno JM et al., “Family Perspectives on End-of-Life Care at the Last Place of Care.”
16 Addington-Hall et al., “Dying from Cancer.”
Chapter 3: How we evaluate our services

Service objectives

Evaluation has always been an on-going part of delivering Irish Cancer Society services. However, these reports mark the first time we have evaluated our services systematically. We have done this by measuring the impact of our services against a set of 5 clear objectives. These objectives are further broken down into 26 outcomes or smaller goals. The outcomes are listed in the appendix.

Our 5 services objectives

We will measure these objectives across all our services on an annual basis. This type of evaluation is known as Impact Monitoring.

Surveys were used to collect data. They contained questions designed to measure the Society’s objectives.

18 “Practical Monitoring and Evaluation.”
Considerations and limitations

As with all studies there are limitations as to what can be achieved and considerations which can affect the findings

Snapshot: We only looked at people who used the services during a certain period. We have to consider that their opinions represent a proportion of our service users and not the entire population.

Willing respondents: The people who responded felt able to talk about a difficult situation. People who may have had a less favourable experience of our service or felt it was too soon to speak of their loss may not have been captured by this survey.

Recall: Families and friends were contacted over 6 months after using the service. It is possible their recollection of events may have been affected by the passage of time since they used the service.

Skip rate: As this was a paper-based survey we could not impose mandatory questions. This meant that some questions were skipped by respondents

How percentages are displayed: All percentages are out of the full population. In order to have complete transparency, the number of respondents who skipped a question will be displayed alongside the percentage. Also for scaled questions the ‘satisfied’ and ‘really satisfied’ answers have been collapsed to show one percentage. This is the same for negative feedback – very dissatisfied and somewhat dissatisfied form a single category in the results.

Anonymising the data: The surveys were completely confidential. Any identifiers have been removed from the information provided in this report and replaced with more generic descriptions
Respondent profile

The first questions in the survey asked for some basic information so we could build up a profile of the people who took part in the surveys.

The picture on the left illustrates what we know about the respondents.

Most of our respondents were:

- Women
- Aged 45 – 64
- Who were the patient’s spouse/partner
- 77% of the patients had a primary diagnosis of cancer

Selection process

In April we sent a survey to families and friends of people who had used the Night Nursing service between the 1 July 2015 and 31 December 2015. We choose this six-month window so as not to burden families who had been very recently bereaved, while also ensuring that the surveys were recent enough so that people could remember their experiences. We had a response rate of 137 people.
Chapter 4: Objective 1 - Increasing emotional resilience

Objective aim

At the Society we are fully committed to ensuring that people have the proper emotional supports in place to deal with the different stages of the cancer journey.

The palliative stage marks an incredibly difficult time for both the patient and their friends and family. While unfortunately we cannot change the outcome we hope through our Night Nursing service we can help to reduce anxiety and make people feel more in control of the situation.

We aim to do this by ensuring that Night Nursing achieves the following outcomes.

Outcomes

1.1 Reduced anxiety
1.2 Increased sense of control over situation
1.3 Increased hope about the future
1.4 Increased feelings of support
1.5 Reduced isolation
1.6 Increased sense of dignity and respect

Outcome 1.1- Reduced anxiety

Anxiety presents itself in many different forms and has many causes, for both the patient and their carers.

Patients worries

For the patient the greatest levels of anxiety were centred on:

- Whether their death would be peaceful and painless
- The emotional and physical toll caring placed on their loved ones
- Whether there were any supports in place to help their friends and family when they passed away
Carers’ worries

For many of the respondents it was their first time to look after someone who was seriously ill. This understandably brought with it a great deal of worry. Common causes for anxiety included:

- Worrying that the patient would pass away when they were resting
- Not recognising when the patient needed pain relief or to be made more comfortable
- Wondering how they were going to cope when their loved one passed away

Fortunately the presence of a Night Nurse had a really positive impact on reducing anxiety. Many different reasons were given for why the Night Nurse helped to reduce anxiety, including:

Putting the patient at ease

The Night Nurse helped to put the patient at ease by communicating what was happening, even when they were not conscious.

This was extremely important in helping prepare the patient for inevitable.

Respondents also commented that the patient was concerned that their friends/families should be supported. Having the Night Nurse present helped to alleviate those worries.

Creating a calm atmosphere

A recurring theme in the responses was the sense of calm associated with the Night Nurse.
Others commented how the Night Nurse made a stressful situation better.

Providing peace of mind

Another common theme was the peace of mind that came with having a medical professional present,

Especially during the night, which could feel like a long stretch to provide care when there was no one else around.

Taking over the burden of care

Having a Night Nurse to perform the clinical role allowed the family to concentrate on the emotional side of care.

This was hugely important for the respondents as they felt preoccupied with this task and ill-equipped for it.

Removing this burden of care allowed them to simply become family and friends again, allowing them to enjoy their time with their loved ones.
Outcome 1.2 - Increased sense of control over situation

A common theme throughout the findings was a feeling of helplessness at the situation. However, there was also a strong thread in the responses that the Night Nurse helped the respondents to have more control over the situation. This happened in a variety of ways.

Preparing the families for the different stages

The Night Nurse helped to reduce anxiety by preparing the respondents for what to expect when their loved one passed away.

Keeping the family informed of new developments helped them to feel more control of the situation.

Other respondents remarked that the Night Nurses’ approach to keeping them informed helped them in preparing to say goodbye.

Providing guidance

The Night Nurse also provided a lot of guidance on how to manage pain.

65% agreed that the Night Nurse helped them to cope with the situation

34 people skipped the question
Respondents remarked that they felt better equipped to deal with caring for their loved ones because of advice provided by the Night Nurse. Being given instructions allowed the family to take ownership of certain tasks.

**Complemented existing care**

Respondents commented that the Night Nurse helped to reinforce the care they were giving. This in turn gave them the confidence to continue in their caring capacity.

**Given strength to continue at final stages of care**

Some participants had cared for the patient over a prolonged period of time. Reaching the final stages of care took its toll. Having a Night Nurse present helped them greatly at this stage.

Others remarked that looking back, they were not coping and this was taking a toll on their health. The Night Nurse helped to alleviate this.

**Prepared them for the final stage**

Respondents were also prepared for the inevitable by the Night Nurse. This helped them to cope better with the situation.
Outcome 1.3 - Increased hope about the future

This outcome wasn’t discussed at any great length in the findings.

However, there were indications that a comfortable death allowed family to cope with the funeral and a peaceful passing helped with the grieving process.

This is an area that may warrant further investigation in the next impact monitoring report on this service.

Outcome 1.4 - Increased feelings of support

The Night Nurses were credited with displaying high levels of empathy and taking a personal interest in the emotional welfare of both the respondent and the patient.
For many, the empathy and compassion displayed went far beyond the nurse’s job remit.

“As with all the family distressing situations there was some difficult moments with tiredness and different opinions. The night nurse made sure we were all on the same page and was very patient and professional.”

Understanding the family dynamic

Caring for someone put families and friends under a lot of pressure. At times this led to tension. Several participants commented that the Night Nurse learned the family dynamics and played a role in helping to relieve the tension by communicating with all the family.

Although one participant commented that more could have been done by the Night Nurse to get to know the family, the vast majority of answers showed that the Night Nurses quickly adapted to their new environment and made a good effort to get to know both the patient and their loved ones.

“She was loving and so caring to mam. We still can’t believe her. We felt as if we knew her forever.”

Easy to talk to

Many respondents talked about how easy it was to speak with the Night Nurse and to ask questions.

“85% agreed they were comfortable talking to the Night Nurse”

(14 people skipped this question)

Being able to talk openly to the Night Nurse and ask for advice brought great comfort.

“We would not have been able to cope without her help. She is always on hand for advice or just a comforting word to both patient and family.”
Words used to describe the Night Nurse

In order to find out if our Night Nursing service provided adequate support, we asked the respondents to select which words best described the Night Nurse. This was a question where respondents could choose more than one answer. Overwhelmingly, the respondents picked the positive attributes. ‘Distracted’, ‘disrespectful’ and ‘unprofessional’ were the other choices. No respondents chose these options. The picture on the left shows the percentage of respondents that picked each word.

Outcome 1.5 - Reduced isolation

No visitors

Caring for someone dying, especially during the night when any visitors have left, can be an isolating time for the carers.

"This end stage was such a help to my mum and it was such a help not to have to face it alone."

The presence of the Night Nurse helped to relieve this isolation.

"Had so much brilliant help from the hospice and our local health centre but having the nurse helped us get through those dark hours of night when no services are available."

Many respondents talked about how isolated they felt were when the home care team had left for the day. Having a Night Nurse present helped to make the nights seem shorter.
Sole carers

Isolation was a particular concern for sole carers. Again, the presence of the Night Nurse played a positive role in reducing isolation.

Outcome 1.6 - Increased sense of dignity and respect

At the Society we feel that all our service users should be treated with the upmost dignity and respect. End of life care is no exception. Many of the respondents were very satisfied with the respect that the Night Nurse showed to both them and their loved one. Respect was demonstrated in many different ways, such as:

Treating the patient as an individual.

Often the service user is not in a position to communicate their needs directly. However, they still retain their sense of self and should be treated like an individual.

Putting the patient first

This was of high importance to the respondents, as they felt the needs of the patient were of paramount importance.
Informing the patient what was happening

Even though a lot of the patients were unconscious, the Night Nurses took the time and had the courtesy to explain what was happening to them. This was viewed as being of great importance to the respondents.

Little touches – holding hands, prayers and pillows

Aside from informing the patient of what was happening, the Night Nurse also made small gestures to acknowledge the patient. These were gratefully welcomed by the respondents.

Although one respondent felt that the Night Nurse could have interacted more with their loved one

Preparing the body

Respondents also remarked that the Night Nurse treated the patient’s body with great respect once they had passed away.

In particular, preparing the patient for the undertaker, a job which undoubtedly would have been very distressing for the families.
Chapter 5: Objective 2 - Improving ability to manage practically and physically

**Objective aim**

While we realise that a cancer diagnosis is a life-changing experience, we also know that daily life does not grind to a halt. Normal life can be stressful as it is, but coupled with a cancer diagnosis it can seem overwhelming.

For this objective we like to demonstrate that people feel supported to overcome the financial and physical hardship that cancer incurs. We want to support families with their practical needs to allow them to concentrate on giving emotional care.

We aim to do this by ensuring that Night Nursing achieves the following outcomes.

**Outcomes**

2.1 Increased access to practical support
2.2 Reduced physical pain
2.3 Increased ability to maintain daily activities
2.5 Those in support roles are more confident in their ability to support those affected by cancer
2.6 Reduced financial burden of cancer

**Outcome 2.1 - Increased access to practical support**

Aside from patient care and emotional support the Night Nurses also provided a great deal of practical support. This includes:

*Making sure the patient is clean, dry and comfortable*

When a person is receiving palliative care they are not in a position to look after themselves.

"She kept my sister clean, and dry and pain free. She held her hand to comfort her.”
By looking after this side of care, the Night Nurse helped to maintain the dignity of the patient. Satisfaction rates were high among the respondents that these needs were being met. They also appreciated having someone on hand to provide practical support like lifting the patients.

Liaising with third parties

The Night Nurse also dealt with third parties on behalf of the family. This was seen as being of huge benefit and removed some tasks for the respondents at an incredibly difficult time for them.

Going beyond the call of duty

Respondents commented on how the Nurses went beyond the call of duty and performed additional jobs after their shift had ended.

Access

Access was an area where the service faced criticism. Many service users felt there was a shortfall in the amount of access they had to the service, namely, the maximum number of nights. Short notice of knowing whether or not night nurse was available was also an issue for one respondent.
Others felt that more access to the service would have had a direct effect on their ability to cope with the situation.

**More advertisement needed**

Some respondents commented that the service should be advertised more, to raise awareness of it.

“Did't realise such a service was so readily available. Will support the fundraising days more often knowing that someone is benefiting from this great service, the same way that mam did.”

One respondent now wants to fundraise to support the service so more people can benefit.

**More collaboration needed with healthcare providers**

Many of the respondents commented that a greater crossover with the palliative team would be beneficial to care.

“As it was only for one night it did not make a huge difference, but had we needed a night nurse for longer I think it would have relieved the pressure enormously.”

“We never knew this service was available. I have been talking about this service endlessly to anyone who will listen to me since dad's passing.”

“Finishing @ 7am in morning and palliative care home care team not available till 9am, 2 hour window with no support.”

“All the nurses were very nice, professional but we had 3 different nurses over 4 nights. Ideally continuity would have been great, little difficult trying to explain to our very ill, confused parent at times.”

**Continuity of nurses**

Aside from access, being able to have care from the same nurse was seen as being of great importance in ensuring a consistent, quality service. This was largely due to the fact that it would be upsetting to the patient by disrupt their routine. Having the same nurse caring for their loved one meant that respondents didn’t have to build a rapport with someone else during a difficult time.
Outcome 2.2 - Reduced physical pain

Measuring pain relief

The respondents were greatly satisfied with the nurse’s ability to recognise a need for pain relief and their ability to administer it. Ensuring that the patient received adequate pain relief was a huge concern for the respondents. One respondent described a lack of adequate pain medication when an unusually large dose was required. This involved calls to the doctor, which concerned the respondent. However, no blame was laid on the nurse in this incident.

Feeling inadequate

Lack of medical expertise often meant that respondents felt powerless and inadequate when recognising a need to administer pain relief. Having the Night Nurse there to carry out this function was greatly welcomed.

Outcome 2.3 Increased ability to maintain daily activities
The importance of sleep

The need for sleep permeated the findings. Catching up on sleep was seen as vital for the respondents, and the presence of the Night Nurse was hugely important in ensuring that they were able to do this.

For friends and family, the fact that they felt comfortable leaving their post to get some rest was an indicator of the high levels of trust they had in the Night Nurse.

Running on empty

For others the sleep was vital as they had reached exhaustion point.

Flexibility to take breaks

Having a Night Nurse also allowed respondents to have some time to themselves and take a well-earned break.
Outcome 2.5 – Those in support roles are more confident in their ability to support those affected by cancer

Often the respondents were the principal carers for the patient. Lack of medical expertise and experience in such matters can add to the weight of an already stressful situation. The service was seen to have a positive impact on carers’ confidence levels.

Confidence increased with experience

For the majority of people, this was their first time caring for someone nearing the end of their life. Others had acted as carers over a period of time.

Carers’ confidence levels tended to correspond with the amount of time they had spent in a caring role. Those people who were already confident had spent a more significant amount of time looking after their loved one. However, even when people had spent a great deal of time – in some cases years – looking after their loved one, they still cited the Nurse as being a great help in boosting their confidence.

Sleep and confidence

Night Nurses only provide care through the night, leaving the family with the arduous physical and emotional task of providing daytime care. Respondents remarked that having a
Night nurse present allowed them to catch up on sleep which made them feel more confident in their ability to care for their loved one during the day.

Night Nurses as reinforcement

Some respondents were from nursing/homecare backgrounds. While they may have encountered similar situations in their professional lives, having a personal connection to the patient added a different dimension to the caring role. For these respondents, having the Night Nurse brought great comfort as they were reassured that they were providing the best care they could. In addition, having a Night Nurse allowed them to detach from having a clinical role and spend more quality time with their family member or friend.

Outcome 2.6 - Reduced financial burden of cancer

Couldn't afford a carer

There was very little in the findings to shed light on the financial implications of providing end-of-life care in the home. One respondent did say that they would not have been able to afford a private carer.

Self employed

When a patient needs round-the-clock care, there is bound to be some impact on carers who are self-employed. This is a subject that we know very little about and which could be an area to further investigate in future reports.
Chapter 6: Objective 3 - Increasing access to treatment and support services

Objective aim

For this objective we want to be able to demonstrate that our services actively engage in signposting people to services. We want people affected by cancer to be more aware of their treatment and support options. And we hope to promote more user engagement with appropriate supports.

For palliative services this is extremely important. Ensuring that people know about and can access the best treatment and supports is vital. Being able to make an informed choice to ensure a peaceful death is incredibly important both for the patient and their friends and families.

We aim to do this by making sure Night Nursing is achieving the following outcomes.

Outcomes

3.1 Increased awareness of treatment and support services available
3.2 Increased engagement with other treatment and support services
3.3 People affected by cancer have more choice regarding the care and support they receive.
3.4 Support available is more suitable for the needs of people affected by cancer

Outcome 3.1 - Increased awareness of treatment and support services available

Time constraints

Just under half of respondents were made aware of support services by the Night Nurses. When people weren’t made aware, the main reason cited was time constraints. Many of the respondents said that the Night Nurse wasn’t with them long enough to pass on this information.
Unsure if they were told

IT can be hard to process information at such a difficult time. Several respondents remarked that they were unable to remember if they had been told about support services. Other respondents misinterpreted the question and thought it referred to an additional service that the patient could have availed of.

Told by other healthcare providers

Where the Night Nurse didn’t give information on support services, many of the respondents remarked that the palliative team gave them this information. Some respondents said they were already aware of the services and therefore it wasn’t necessary for the Night Nurse to tell them.

Outcome 3.2 - Increased engagement with other treatment and support services

Following on from the last outcome we wanted to see if respondents did use other support services. Many respondents commented that although they had not used supports services, they would consider using them in the future.

What services people used

Respondents used:

- Cancer support centres
- GP support
- Local bereavement support groups
Community health nurse
Social worker

Non formal supports

Many respondents were relying on less formal means of support. The most common form was talking to family.

Aside from relations, friends in the community were seen as a valuable support. A number of respondents sought solace in religion, which provided them with great comfort.

Peaceful passing

Others did not avail of services because they were prepared for their loved one’s passing.

Outcome 3.3 - People affected by cancer have more choice regarding the care and support they receive
Strong wish to be at home

Some of the friends and families talked about how their loved one had a strong desire to die at home and were able to articulate this.

Fear of hospitals and clinical environments

A recurrent and strong theme was a fear of dying in hospital.

Many of the respondents commented that their loved ones had a strong disdain for hospitals and they were determined to honour their loved one’s wishes not to be placed in this environment.

Wishes were not discussed

Often friends and families commented that the death was more sudden than anticipated. The conversation about dying at home was never discussed. However, in the majority of cases the family and friends expressed that they knew it was the wish of their loved one, even when it wasn’t articulated.

Family and friends wanted their loves ones at home

In the absence of a direct request from the patient, the families and friends themselves expressed the wish to have their loved ones at home.
While we know that the majority of patients wished to die at home, not everyone would be in a position to do this. There are several reasons for this:

**Lack of experience**

Lack of experience looking after someone so ill was the most common reason given.

**Family supports**

Those who did have the option of remaining at home, with or without a Night Nurse, did so through a large amount of support, mainly from family members.

However, even with a large amount of support, numerous respondents felt that the assistance of the Night Nurse was incredibly helpful.

**It would be a great strain**

The most common response was that their loved one’s wishes would be facilitated, with or without the Night Nursing service. But without the presence of the Night Nurse this would have been a more arduous task.

**Medical background**

Some respondents were in a position to look after their loved one because they had a nursing background.
Short-term care

Others felt they could facilitate the request as it took place over a short period of time.

“SHE WOULD NOT GO TO HOSPITAL NO MATTER WHAT.”

Determination

Others managed through sheer determination to keep their loved one at home.

Outcome 3.4 - Support available is more suitable for the needs of people affected by cancer

Respondents felt the home setting was a more suitable place for end-of-life care for a variety of reasons.

“She died surrounded by her children and grandchildren. That just would not have been possible in hospital.”

More family presence

The home setting allows for greater flexibility around the presence of visitors and carers. In a clinical environment there would be far more restrictions on how much time and how many family members could be present in the room.

Respondents spoke of the importance of having family present, especially small children and pets, who may not have been welcome in a hospital.

Having more family members present also allowed for more quality time.

“We just had the night nurse on the night Dad passed away, but if it was to go on past that it would have been a must.”

“Of all the services offered - this proved the most helpful and supportive, I was allowed to lie with my daughter and sleep while the nurse observed the patient throughout the night previous to her death.”
Non-intrusive

The service was also credited with being non-intrusive, enabling families and friends to spend time with their loved one.

Privacy

The home setting also allowed for greater privacy than hospital, which was of great value to both patient and their loved ones.

Comfort and familiar surroundings

Aside from family, another common theme was the wish to pass away in familiar surroundings.

Local care

Some of the respondents commented they knew the Night Nurse from the community and that familiarity brought comfort.

Also this meant that families did not have to travel large distances to spend time with their loved one.
Chapter 7: Summary

The findings of this survey demonstrate a definite need for palliative care at home and the Night Nursing service. Some of the key themes that emerged were:

**People want to die at home**

The vast majority of people who took part in the survey agreed that the home setting was the preferred place for end-of-life care. In many cases it was the last wish of the patient. In other instances, where the patient could not communicate their family and friends felt it was imperative that they spend their last days at home. A fear of hospitals and clinical environments was the principal reason for this decision.

**Family members are determined to facilitate wishes but are ill equipped to do so.**

Respondents felt a heavy sense of duty and responsibility to facilitate end-of-life care at home. However, most of the people who took part in the survey had little experience of such situations. The physical and emotional burden of care on them was great. Many respondents felt overwhelmed and exhausted, with lack of sleep cited as a major barrier to providing adequate care. Many respondents talked about being at the burnout stage and struggling to cope by the time the Night Nurse arrived.

**Taking over the Clinical Role is a great relief to the friends and family**

The arrival of the Night Nurse helped to make a real difference in reducing anxiety levels. Taking over the clinical role greatly reduced the burden of care on friends and family. The respondents were extremely satisfied about the level of clinical care they received.

Fear of dying in a hospital was a common theme. Family members are determined to facilitate wishes but are ill equipped to do so. Taking over the Clinical Role is a great relief to the friends and family.
care administered, especially in terms of pain relief, as this was an area many felt intimidated by. The Night Nurse helped to relieve this worry by keeping the respondent abreast of the situation. Having a nurse to take care of clinical matters allowed friends and family to concentrate on the emotional side of care.

Night Nurses support the entire family

What is evident from the findings is that the Night Nurse, in a relatively short space of time, builds up a trust and rapport with the families, which allows them to hand over the mantle of care and get some much needed sleep. The bond formed with the Night Nurse was incredibly strong. Throughout the surveys, respondents thanked individual Night Nurses by name. This tells a great deal about the positive impact the Night Nurse had on them during this incredibly difficult time.

For the patient, pain was well measured and the Night Nurse took time to treat them as an individual. The nurses took an invested interest in their charges and great levels of empathy were shown to both patient and their families. The patient felt at ease with the nurse and this helped prepare them for the end of their life. Many respondents commented on a peaceful passing, which in turn helped them to cope in the aftermath of the death.

More access is needed for the service

The only real criticism levelled at the service was the about the number of nights of nursing care available. Many respondents felt that increased access to the service would reduce the physical and emotional burnout they were feeling and help them to cope better with the situation.

Long term benefits need to be investigated

An interesting avenue for further research would be to compare the experience of the families of Night Nursing patients to those who died in a clinical environment. This would allow us to see if users of
the Night Nursing Service report a more favourable dying experience and an easier grieving process. A study like this would lend evidence to show that the service has positive impacts in both the short and long term. The findings of the current study show clearly that the service is valuable one, which truly has a positive impact on the lives of the people who use it.

**Conclusion**

Overall satisfaction with the service is high. The Night Nurse not only facilitated the clinical role but also provided great comfort to the patient’s friends and family. This greatly increased their emotional resilience and prepared them for their loved one’s passing. For the patient it allowed for a dignified death.

The Night Nursing Service has proven is a crucial and necessary component of palliative care in this country.

**Most common words used in the surveys to describe the service**
Appendix
Irish Cancer Society outcomes framework

Objective 1
Increased emotional resilience of people affected by or worried about cancer

Outcomes
1.1 Reduced anxiety
1.2 Increased sense of control over situation
1.3 Increased hope about the future
1.4 Increased feelings of support
1.5 Reduced isolation
1.6 Increased sense of dignity and respect

Objective 2
Improved ability for people affected by or worried about cancer to manage practically and physically

Outcomes
2.1 Increased access to practical support
2.2 Reduced physical pain
2.3 Increased ability to maintain daily activities
2.4 Increased likelihood of attending medical appointments
2.5 Those in support roles are more confident in their ability to support those affected by cancer
2.6 Reduced financial burden of cancer

Objective 3
Increased access to treatment and support services appropriate to the needs of people affected by or worried about cancer

Outcomes
3.1 Increased awareness of treatment and support services available
3.2 Increased engagement with other treatment and support services
3.3 People affected by cancer have more choice regarding the care and support they receive
3.4 Support available is more suitable for the needs of people affected by cancer
Objective 4
Increased knowledge about cancer and its symptoms and treatment

Outcomes
4.1 People affected by cancer have increased knowledge about cancer and its symptoms and treatment
4.2 Those in support roles have increased knowledge about cancer, its symptoms and treatment
4.3 Family members and friends are more knowledgeable about cancer and its symptoms and treatment

Objective 5
Increased awareness of cancer risks and preventive behaviour

Outcomes
5.1 Behaviours that increase the risk of cancer are perceived as less desirable
5.2 Increased motivation to change/maintain behaviour
5.3 Those wishing to change/maintain their behaviour feel more supported/able to do so
5.4 Behaviours that increase the risk of cancer are reduced
5.5 Behaviours that reduce the risk of/detect cancer are increased
5.6 Medical help is sought more quickly once symptoms are identified
5.7 Increased knowledge about risk/preventive behaviours


