THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST

Specialist Palliative Care Team

Report of Patient and Carer Satisfaction Survey 2011

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Patient and Carer Satisfaction Survey within Specialist Palliative Care
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Introduction

The Specialist Palliative Care Team in Newcastle Upon Tyne Hospitals NHS Foundation Trust is committed to providing high quality palliative care to patients and their carers. The Team works out of 3 bases across the Trust; Royal Victoria Infirmary, Freeman Hospital and the Northern Centre for Cancer Care. In order to evaluate the quality of the service provided and identify ways of improving practice a Patient and Carer Satisfaction Survey was completed between November 2010 and March 2011.

The aim was to have an overview or “snapshot” of how patients and carers viewed the current service providing an opportunity to improve and if necessary change where required the quality of service provided.

The team hoped that the patient and carer satisfaction survey would help us identify ways of improving our practice which ultimately translates into better care and happier patients.

Methodology

Members of the service development sub-group from each identified team met to formulate the questionnaires. The following principles were agreed:

- We needed to ask at the very least about the top 3 issues identified in the literature as being important to patients. Components of care repeatedly evaluated as extremely important by patients are:
  - Communication of information
  - Personal treatment by staff
  - The degree to which they feel involved in their care
- Generally, patients are more likely to answer survey questions honestly if they believe their identity is protected. Every effort was made then, to keep the entire survey process anonymous. Patients should be able to complete their surveys in private and return them without fear of being identified.
- The questionnaires should mirror a similar survey done in the community by the Newcastle Upon Tyne Community Specialist Palliative Care Team for validity.
- We should aim to survey an average of the equivalent of 1 months worth referrals to the teams on each site to get a reasonable “snapshot” around 30 -35 questionnaires
- A verbal explanation of the reason for the questionnaire would be given and a request for participation with a “cooling off” period prior to the questionnaires being handed out.
• The questionnaires would be administered by an alternative key worker to ensure anonymity towards the end of inpatient stay with a minimum of 2 visits/input from the SPCT.

• The patients and carers could complete the questionnaires and leave in a plain envelope for collection later or could take them away and post the completed questionnaire at their leisure. Help was offered to complete the questionnaire by the alternative key worker if required.

• While we don’t have to act on every suggestion that patients give, we would take action on the key items that are causing dissatisfaction. Remembering that the goal is to improve quality, not to place blame.

Results

RVI Carer Questionnaire (11 returned)

Questions and comments:

1) Did you feel that the Specialist Palliative Care Team listened to and understood the needs of the person you care for?

- If not available on ward you could contact and they would come and listen to concerns or phone back taking our views into account.
- Took their time and listened.
- Considerate and caring. Patient at centre of every decision.
- Understood patient well. Helped her to decide to go to hospice for specialist treatment so she could go home to new house.

2) Did you feel that the Specialist Palliative Care Team give you the opportunity to share your views or worries about the person you care for?

- Listened and gave advice as best they could.
Data protection has to be observed.
Had a full discussion – all family involved.
Always ready to listen.

3) Did you feel you were given the opportunity to talk about your role as a carer and its effects on you?

With the patient endeavoured to bring into conversations how help could be given but helped with enabling patient to understand that help often needed even if they themselves are worrying about the carers.
They are very understanding, helpful and compassionate.
Many opportunities to meet and discuss concerns.

4) Did you feel the Specialist Palliative Care Team gave you support?

Gave me all support I needed as far as they are able to but ultimately the patient is their main concern helping them to deal with their fears.
Gave full support and telephone numbers to contact.
Gave full support.
Once we were put in touch with team we were satisfied. Unaware there was a team.
Discharge number left and reassurance they could be contacted when patient had left the ward.

5) Would any information in carer support available within your area have been useful?

You only become aware when it’s someone in your family needing support.
You are given help and information to guide you.
Have not had any information for the home area.
Maybe some leaflets to read.
Large family with great support.
Quick transition from terminal diagnosis to hospice.
Difficult to know what information would have been useful.

6) Are you satisfied with the service you have received from the Specialist Palliative Care Team?

Very satisfied.
Limited service but they do try to give their time as much as possible.
Satisfied with advice so far. Main care and support will take effect when we get home.
It was (naturally) based more on needs of patient – or so I thought.
Support and guidance has been invaluable to my father and family.

7) And finally……

Don’t think you could improve service as so good.
It is very difficult to take everything in when first finding out about illness. Sometimes questions you would like to ask are forgotten. Also it’s difficult talking in
front of loved ones possibly some clarification out of earshot would possibly be helpful.

- We understand the patient has to be involved in many decisions, but husband was confused and found the process very emotional. Some time alone with the PCT would have been good for us and less distressing for husband.
- Thank you for support and compassion!
- Make people aware of the team when they first come into hospital.
- Have made a difficult time easier. Solution found to a complex pain issue that may not be found otherwise.
- Difficult to say.

**RVI Patient Questionnaire (16 returned)**

![RVI Patient Questionnaire](chart)

**Questions and comments:**

1) **Did the Macmillan Nurse/Doctor show you respect and help to maintain your dignity?**

- Very pleasant.
- Made me feel at ease.
- Always courteous and respectful.
- Listened to what I had to say.
- Helpful, kind and supportive.
- Very good and sympathetic.
- Well informed, bright and friendly.
- Spoke to me directly and took their time.

2) **Did you feel involved in decisions regarding your care provided by the Specialist Palliative Care Team?**

- Opinions asked and noted upon.
- Made sure I understood what they had been telling me.
• Let me make my own decisions.
• Took on board ideas, enquiries and followed up with information asap.
• All questions and needs addressed. Lots of opinions and cause of action given.
• Discussed everything but some days I was confused so couldn’t understand.

3) Did you feel able to talk with the Macmillan Nurse/Doctor about any problems you might have?

• Treat with much respect and willing to assess any problems.
• They make you feel comfortable enough that you can tell them anything.
• Always willing to listen and give feedback. Encouraging. Easy to talk to.
• Helped a lot as down in mood. Many topics from practical matters to faith. Very pleasant with me.

4) Did you feel that the Macmillan Nurse/Doctor listened to and understood your needs during their visits?

• Very thorough when asking about my problems.
• They clarified everything. Willing to discuss as much as I wanted and more.
• Satisfied.
• I could not always make myself clear.

5) Are you satisfied with the service you have received from the Macmillan Nurse/Doctor?

• Very pleasant indeed. They are very good, kind, polite, understanding and helpful.
• Very satisfied. Wonderful analysis of problems and concise explanation of causes and conclusion to resolve difficulties.
• Although my philosophy had encompassed the ‘future’, I was made aware of help I didn’t know was available.
• Most definitely.
• Not sure what to expect at home.

6) Did you receive an explanation about the role of the Specialist Palliative Care Team?

• Very informative.
• From the nurses.
• The doctors and nurses on the ward advised me.
• PCT explained about the role.
• Excellent.
• Not sure if I understood anything – confusion.

7) Would any other information have been helpful?

• Difficult to say.
• Enough information – didn’t know what else needed to know.
• Happy that all questions were answered.
• How would I know?
• Given a thorough introduction to teams function.
And finally…….

- Very grateful for all the sterling work.
- Brought some calm and composure to our visits.
- Always had insight into what was the real issue. Didn’t push; let you come to that in your own time.
- Nothing but praise for the treatment by the PCT, Drs, nurses and ward staff on ward 31 RVI. Thank you.
- Excellent review by RVI doctor.
- Happy.
- Would like to know when things are happening.
- Specialist nurse made me feel well supported – I’m looking forward to the future.
- Too many questions and information for me to digest. Found it very frustrating that I could not always understand.

Freeman Hospital Carer Questionnaire (11 returned)

Questions and comments:

1) Did you feel that the Specialist Palliative Care Team listened to and understood the needs of the person you care for?

- Really felt they cared.
- Helped my mum understand more about what was going on and reassured her about options she had.
- Helpful and listened.
- Very understanding.
- Helped my dad by explaining treatment, answering queries and helping to improve the co-ordination of treatment – they have supported him emotionally.
• Yes, from medical care to paperwork.
• Very busy but always time to talk.
• Always, whatever mood he was in she would a smile for him.

2) Did you feel that the Specialist Palliative Care Team give you the opportunity to share your views or worries about the person you care for?

• Listened to my concerns. Helped reassure me.
• As a family we worry everyday when we say goodbye.
• Care about your fears and worries.
• Helped us enormously to know someone has been there to help him.
• Nothing has been too much bother.
• Whenever I rang with a question, however difficult, I always got a satisfying answer.

3) Did you feel you were given the opportunity to talk about your role as a carer and its effects on you?

• Travelling to Newcastle everyday from Whitley Bay was difficult.
• Always asked how you were coping and needing help yourself.
• Not needed up to now.
• Very caring and listened.

4) Did you feel the Specialist Palliative Care Team gave you support?

• Always at hand when help is needed.
• Don’t think treatment would have progressed as quickly or effectively without your support and intervention. We would be lost without this team.
• The support with OT has been most effective as proved by weekend at home.
• Strong support given at a difficult time. Appreciated how team sorted out problems when they arose.
• Helen has supported me every step of the way during my mam’s stay in hospital, always explaining everything that was going on with my mam.
• Always there to listen – when and where was not a problem to her if needed.

5) Would any information in carer support available within your area have been useful?

• Informed of carer support would definitely help. Been a carer for 20yrs and to know what’s available would be added reassurance.
• Whatever help or advice is needed, always available.
• Macmillan nurses are involved and we may ask for more info in the future.

6) Are you satisfied with the service you have received from the Specialist Palliative Care Team?

• Excellent team members.
• Lovely people.
• Big thank you.
• Always available when problems arise.
• Numerous helpful conversations often on minor items which were very helpful to someone unfamiliar with hospital routine, staff roles and responsibilities and who should be contacted.
• The whole family would like to thank the palliative care team for their help and understanding, care and concern.
• 100% satisfied.
• Ann Marie Somerville is a credit to the team.

And finally…….

• I went home feeling much better.
• Time and support they gave to my sister and I was the best. Excellent.
• I sat 3yrs ago with my dad, same illness. I only wish we could have had this help and support then. I live day to day with my mum’s illness.
• Everything up to now has been supportive.
• Helen has made this experience so much easier for us as a family to cope with.
• Everything that has been said to us has always been said in a way that anyone could understand.
• No need to improve.
• Your team have provided excellent care. We are grateful that you have been there for us – we do not see how the service could be improved.
• Maintain the standard of selection, training and aptitude of the Macmillan staff that I have dealt with.
• On the night he died, we would have appreciated a quiet room together rather than a curtain round the bed on a difficult ward. The staff were doing a tremendous job under trying circumstances, but other patients were noisy. My husband had several items taken from him and in his dying moments we had to listen to some foul language which was unacceptable. I know it’s not the team’s problem but any back-up you can give to sort this out would be of enormous benefit to future patients.
*Freeman Hospital Patient Questionnaire (16 returned)*

**FRH Patient Questionnaire**

Questions and comments:

1) Did the Macmillan Nurse/Doctor show you respect and help to maintain your dignity?

- At all times.
- I don't think I would have survived mentally and physically to such a good level without their sympathetic support.
- Respectful.
- Always felt a partnership. Always felt empowered.
- My nurse Helen was always polite and respectful and spoke in a way I understood.

2) Did you feel involved in decisions regarding your care provided by the Specialist Palliative Care Team?

- Kept checking I was happy with what was suggested.
- Questions were answered concisely and in plain English.
- About existing meds and alternative use.
- Felt everything we did was a team decision. Never imposed upon me.
- Each new development explained.
- Every decision made was always put to me first.

3) Did you feel able to talk with the Macmillan Nurse/Doctor about any problems you might have?

- Very much so, to both Dr and nurse.
• Very sympathetic and empathetic help. No one told me what to think or do to resolve my problems. They helped me get my mind straight and start working out my own personal solutions to the difficulties facing me.
• Got a lot of things off my mind. Helped me over my problems.
• Wonderful listener. Always felt time for me and was interested in concerns no matter how small.
• Nurse left her card for me to contact when needed.
• Able to discuss welfare and mental problems. Had a traumatic three weeks and couldn’t have got through it without their help.

4) Did you feel that the Macmillan Nurse/Doctor listened to and understood your needs during their visits?

• Kept checking what I said.
• Absolutely and completely.
• Willing to listen to and needs and changed planned purpose of visit to fit these as well as being a good talker, had always time to talk to me.

5) Are you satisfied with the service you have received from the Macmillan Nurse/Doctor?

• While an inpatient at Freeman yes.
• I could not have ever begun to think how helpful this has been and I am looking forward with renewed confidence to working with the Macmillan team who are supporting the whole family at home.
• Would like to adopt my Macmillan nurse and take her home.
• Can’t complain.
• Have been on four different wards and they have provided continuity of care throughout.

6) Did you receive an explanation about the role of the Specialist Palliative Care Team?

• Yes, which was helpful, as you wonder how they fit into staff on the ward?
• Clear and concise explanation and it was made clear there were no objections to supplement questions.
• They listened to all the concerns I talked about.
• They explained everything.
• Yes, explained difference between acute pain unit and palliative care team.

7) Would any other information have been helpful?

• Have always been given any information asked for.
• It was treated with care and consideration. Thank you.
• They were very good.
• Information at appropriate level for my needs at home.
• I was told everything.
• Perfectly happy. Further appointment arranged in hospital.
• Helpful in all ways.
• Information about jaundice levels.
• Written information would have been helpful to read it in my own time.
• All information more than adequate.

And finally……

• Macmillan nurses are: caring, sensitive and understanding. No problem too small or large for them. If they don’t have the answer, they will find out.
• Nice to have experts on hand and you do not feel stupid saying things to them and may clarify issues you have.
• Both doctors and nurses were excellent in their explanation and they had time to listen. I never felt I was taking too much of their time.
• What lovely people to deal with. I really look forward to continuing relationship with my Macmillan Palliative Care team.
• Very grateful.
• Would like to have continued relationship once have left the hospital.
• My nurse Helen was so very helpful to both myself and family I could not praise her or the Macmillan service enough. 5 star service at all times.
• Nothing but praise for work of this team. Would have found the last three weeks ever more difficult without their constant help and encouragement. Their understanding of the needs, mental and physical of cancer patients was most reassuring.

NCCC Carer Questionnaire (17 carers)

![NCCC Carer Questionnaire Chart]

Questions and comments:

1) Did you feel that the Specialist Palliative Care Team listened to and understood the needs of the person you care for?
Yes very much so – discussed options at length and came to an agreement of care.
Yes very supportive and understanding
Yes – seemed interested.
Yes they understood everything.
Yes very understanding and helped with pain management excellent
Yes they give you time to speak about what's really bothering you or any problems relating to the condition.
Everyone who we have spoken to throughout the whole team have been exceptional.

2) Did you feel that the Specialist Palliative Care Team give you the opportunity to share your views or worries about the person you care for?

They always asked if we were happy or had any questions.
I wouldn’t know where to find anyone to discuss matters with.
No – not here all the time when I visited due to work commitments.
Always reassuring and patient to listen. Feel they do the very best to understand me and help to understand situations.
Yes, they helped us to sort out any problems we had. They are very helpful.
This service is fantastic, could not ask for any better communication.
They took the time out to listen and to care.

3) Did you feel you were given the opportunity to talk about your role as a carer and its effects on you?

We did not discuss this.
No – not here all the time when they visited due to work commitments.
I am not the carer, but they asked how I cope and what they can do to help.
Unwavering support and advice enabling a trust bond to develop with any member of the team.

4) Did you feel the Specialist Palliative Care Team gave you support?

Brilliant support provided when my wife was seriously ill and our daughter was due to start a new job. Everything was explained to her employers and a new start date arranged.
Felt I could ask for help if I needed any.
Yes I was very pleased with the support they give me.
Very much I never had such personalised help with the pain before but then I didn’t know there was help available like that.
Yes I’m sorting some financial worries and all other things that worries us. They are very helpful.
Assured me I could contact them at any time to discuss any concerns I have.
More support than we ever imagined was possible especially Diane and Karen.

5) Would any information in carer support available within your area have been useful?
• I have been in touch with the Macmillan Nurses in our community
• They have put me in touch with the local carer in my area, with a visit from them it give me comfort that there is help closer at hand.
• I feel that once a relative is diagnosed they should be given a direct contact number or nurse just in case needed, this would help build a relationship with each other – whether it is required by the carer or not at least it would be there.

6) Are you satisfied with the service you have received from the Specialist Palliative Care Team?

• Very much – very helpful and caring to ensure my partner was comfortable as possible
• I am very grateful
• Completely amazing doctor and nurse team
• Yes very satisfied without them we cannot understand fully my condition regarding my illness.
• Can’t praise our personal Macmillan nurse highly enough. If she says “leave it with me” you know she is going to sort everything out and speedily. She has been brilliant.

And finally…….

• Nothing – it all worked perfectly for us
• It would be helpful to have a definite appointment to discuss needs, views and worries. Discussions with me were by chance.
• I can’t think of any way they could improve, they were very good
• I cannot think there need to be anymore improvement to me they are the very best friendly caring people.
• The only way it could be improved (and I know it’s not possible), would be to have out of hours contact and weekend and contact. Often you just need to ask advice at these times and can’t
• I could not ask for any better service than was being given at the present time.
Questions and comments:

1) Did the Macmillan Nurse/Doctor show you respect and help to maintain your dignity?

- Very kind and helpful
- I cannot speak too highly of all the nurses
- Yes, professionally all the time on the treatment
- The nurse who came to see me was excellent. She give me so much help and information, I was most pleased to have seen her
- My Macmillan nurse was very respectful and courteous at all times.
- They always spent time to listen to what I had say
- I felt that the concern and respect was fantastic
- At all times

2) Did you feel involved in decisions regarding your care provided by the Specialist Palliative Care Team?

- Mutual questions were made on course of action and drugs. Expert advice was given but I still felt that I had the final say/decision.
- All options discussed in detail
- I was kept informed of everything that was happening
- They let you know what’s going on and choose what is really good for my treatment
- Yes I got help on practical things as well as my illness
• We had good discussions on appropriate care with sufficient information to answer the questions that we asked (both myself and my husband).
• The decisions during the early part of the procedure could easily be understood, but the whole picture was difficult to see in the end result.
• Most definitely

3) Did you feel able to talk with the Macmillan Nurse/Doctor about any problems you might have?

• Everything was explained if I was unsure about anything.
• Extremely friendly and open/honest from the first meeting. I therefore felt I could discuss any problems.
• Very easy to talk to.
• I feel as though the nurses have been so supportive and nothing has been too much trouble.
• My Macmillan nurse was very supportive and very caring I feel comfortable when asking so many questions and she explained very well.
• Most certainly I gained a great deal of satisfaction from our talks.
• I also felt that the needs of my family were also taken into account and advice/contact info given as appropriate.
• My Macmillan nurse is very approachable and helps resolve any issues and concerns I may have had.
• Yes very much so in two way situation.
• Yes the team are very understanding and deeply caring.

4) Did you feel that the Macmillan Nurse/Doctor listened to and understood your needs during their visits?

• Very much so. Brilliant service.
• Yes they have been brilliant.
• Again she understood my situation at home, living alone and having to cope and get the help I will need when I go home.
• My nurse listened to all my comments and acted on them quickly and efficiently when required.
• I felt the nurse listened not only to me but my family also who are very impressed with the way I was handled.
• Yes, most certainly. Having been sick for approximately eight weeks I was desperate for some relief from vomiting.

5) Are you satisfied with the service you have received from the Macmillan Nurse/Doctor?

• Yes a 100%.
• They have been brilliant. I just don’t know what I would have done without them.
• Yes I was more than satisfied and look forward to seeing her again. She was really most helpful.
• They have been a big help in getting pain relief optimised.
• Yes more than satisfied – the level of knowledge and information provided was excellent. We have every confidence in the team.
• Yes extremely so.
• Yes the nurse suggested a change in tablets and now the sickness has gone

6) Did you receive an explanation about the role of the Specialist Palliative Care Team?

• Yes at first meeting
• Again I found them to explain themselves so well
• Though there is a lot to take in at first I’m sure I’ve gained from our meetings
• Yes names and contact numbers were provided for ease of contact.
• Yes, they were very caring

7) Would any other information have been helpful?

• I have received regular meetings so had ample opportunities to ask for more info if required. I was also provided with contact details for between meetings for any further questions/requirements I may had
• Everything was discussed in great detail
• I feel everything was fully explained to me
• My Specialist Palliative Care Consultant was very helpful, she’s the one who explained well everything what’s going on with my treatment, my condition especially my feelings regarding my condition
• No all relevant information was provided during visits.
• We discussed on a number of times my adverse view of medication talking, to a high level of agreement, but I don’t like the situation I am in at this present time.

And finally……

• I have no further suggestions – I would just like to express my gratitude for the service I received
• Don’t know where I would be without you. Thank you so much for all your help and support
• I think the nurses do a wonderful job and I for one would have been lost without them in particular Angela has been marvellous
• I should say, whenever we have to see my palliative care consultant, I have a great knowledge and feel more aware regarding my illness and more understanding what’s going on. I feel more relaxed and confident that you are in safe hands and healing you.
• Whilst having a chest drain I asked if the Macmillan nurse would stay with me for the procedure. I found this invaluable and very helpful that she was with me for this procedure; I don’t think I could have got through it without her. This demonstrated not only technical ability but also a compassionate understanding of the situation
• The service provided by the Macmillan Nurses is very good
• I think they do a fantastic job, very caring and have always got time for you without rushing and are sensitive to the illness. They gave reassurance and comfort
• Julie Dixon, Macmillan Nurse has been a wonderful support and very helpful getting everything sorted and moving quickly. She has also been a
great help to my family and I don’t think she could have done anything more, she has been wonderful
- The service is extremely good
- I have been told everything I wanted to know
- I am extremely pleased with the care and attention shown throughout my care

Conclusion and Recommendations

The majority of carers and patients who responded to the survey expressed extremely high levels of satisfaction with the nursing and medical staff within the Specialist Palliative Care Teams. They told us they feel involved in their care and communication is good.

In terms of service improvement the following recommendations could be made:-

1. Following consent from the patient about sharing information a separate appointment to discuss concerns and issues is offered to carers with a member of the Specialist Palliative Care Team.

2. All carers should be offered the Macmillan support booklet “Hello and How are you?” which is written by carers for carers

3. At present there is no facility to offer a contact number for out of hours advice but this should be highlighted to health care commissioners as a gap in service provision for future strategic planning.