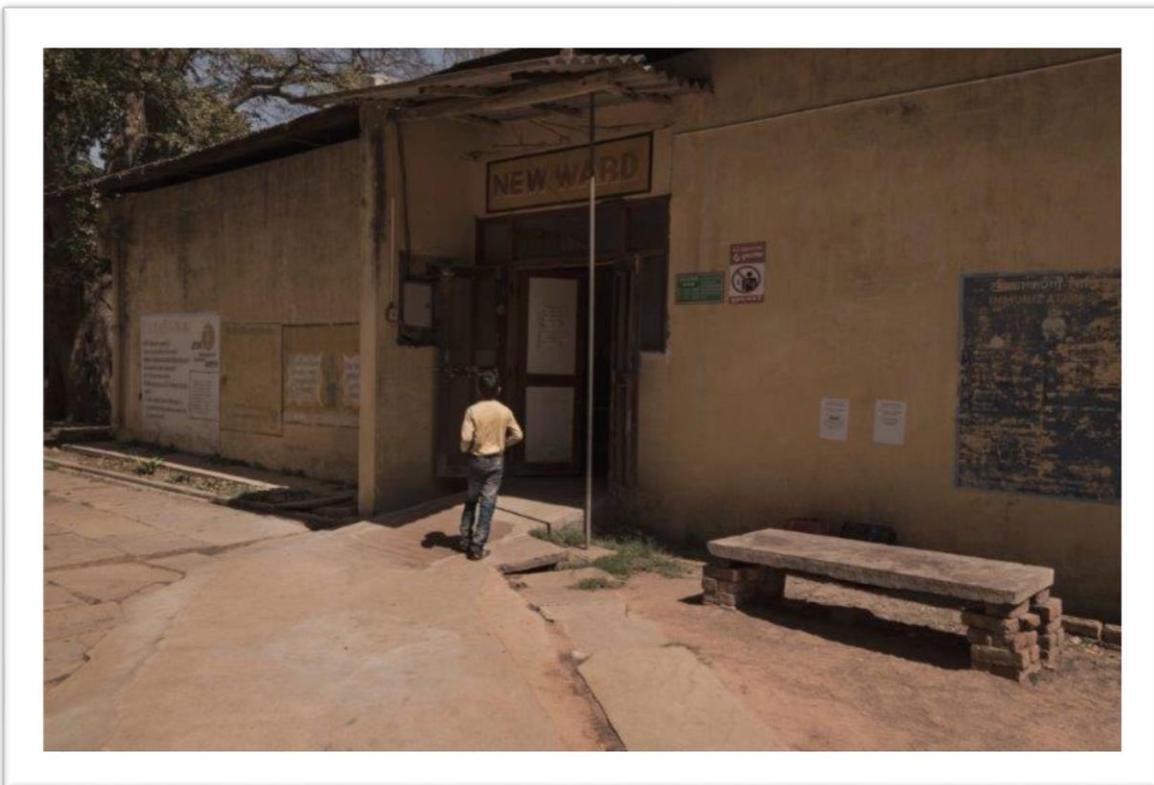


## Report on visit to Harriet Benson Memorial Hospital Lalitpur, Utter Pradesh, India



**When:**

Date of visit: 6 - 17 March 2017

**Who:**

Kim Donaldson; Hospice Practice Development Facilitator and Lorraine Wilson, Community Palliative Care Team Leader

# Report on visit to Harriet Benson Memorial Hospital

## Purpose

To support palliative care delivered in a community setting in rural India.

## Background

The visit was arranged following an evaluation of palliative care services carried out by EMMS International (Haralddottir and Mundy 2015) where one of the recommendations was to support practice through education, clinical placements and mentorship visits.

Harriet Benson Memorial Hospital (HBMH) is part of the Emmanuel Hospital Association (EHA), a charitable organisation delivering healthcare in North India. HBMH provides general, obstetric, public health and palliative care services to people in and around the Lalitpur district, Uttar Pradesh.

The palliative care team was established by Dr Anne Tyle in 2009. Originally designed as a community model it went on to open a dedicated palliative care ward in 2011. The current medical cover is Dr Toni, who is onsite with Dr Savita overseeing the project from Delhi. The palliative care team also consists of: Leelha (lead registered nurse: currently semi-retired and working part time), Sarjo (senior registered nurse: full time), 1 further registered nurse, 2 nursing care assistants, a driver, an administrator/coordinator and a registered nurse in training on a probationary basis.

The Lalitpur team was the first palliative care team within the EHA serving North India. Its model has been adopted in other hospitals within the organisation.

The team won 1<sup>st</sup> prize in the International Journal of Palliative Nursing Excellence Awards in 2013.

The HBMH hosts education events for Indian Association of Palliative Care in a purposely renovated building.

## What we did

At the EHA headquarters we met with Mr Ajit and Ms Sunita to learn of the current work and of the background to the organisation. The expectations of being a volunteer were fully explored. Mr Ajit and Ms Sunita ensured we had the necessary travel documents and instructions for our train journey to Lalitpur. At this point we also had the opportunity to meet Ms Sarah who although was non clinical and based in Delhi had extensive experience of visiting and working with the palliative care team on site.

We also met with Dr Savita, who oversees the delivery of palliative care within the EHA. Dr Savita replaced Dr Anne Tyle following her recent retirement. Dr Savita is keen to

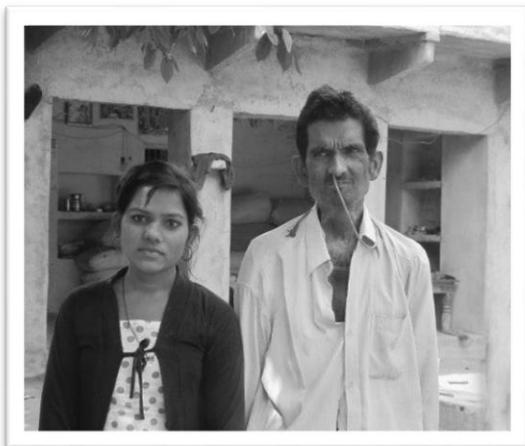
further develop existing services and requested we observed practice and offer feedback on areas for development. She was aware of the emotional impact of the work and asked we considered this when working with the team.

Once in Lalitpur the first 3 to 4 days were spent getting to know the team, building relationships and trust. Three languages were spoken, firstly Hindi, then English as a second language and lastly Telugu was the first language of a registered nurse currently training on the palliative care team who was also learning Hindi. Not all staff were able to speak English. We relied on those who could speak English to interpret for those who could not. All patients and families we meet spoke only Hindi.

We adopted a positive enquiry approach in order to establish current practice and build relationships.

These initial few days were spent shadowing the team. We were invited to and attended a ward round of the full inpatient unit and of the palliative care ward to gain insight into the overall remit of the hospital. Much time was spent with the community team going out on home visits and entering into clinical discussion and reviewing patient's notes with the team. Part of the work of the palliative care team was to do health education in the form of awareness sessions in Lalitpur and surrounding villages. We witnessed these sessions being well received and an opportunity for people to self-refer.

Many episodes of excellent care were witnessed and a lot of learning of how palliative care in Lalitpur had many similarities and yet was different at the same time to practice back home. The core principles of taking a holistic approach and attending to the physical; psychological; social and spiritual elements of palliative care were clearly evident aligning to what we believe we deliver in Scotland. The availability of drugs and the route of delivery although very different to palliative care in Scotland is in alignment with the Hospice UK: Palliative Care Toolkit for resource limited settings (2009).



Many patients cared for had a fungating lesion and the availability of dressings is limited. Towards the end of life and for those unable to take oral medications earlier in their disease nasogastric tubes are used for the delivery of medication. Medications are crushed and administered independently or by family members. The use of the subcutaneous route is limited and not available in the community. The Hospital have three Graseby MS 26 syringe drivers which cannot be used presently due to a lack of knowledge and equipment.

Towards the end of week one we were asked by the palliative care team to hold a complications of the 'bed ridden' patient teaching session for the inpatient nurses. As we were still building rapport and trust we were keen to oblige however did not want to alienate nursing staff by teaching the basics. An interactive workshop asking participants to draw on their own knowledge and skills incorporating assessment tools used at St Columba's Hospice was developed and delivered. The session was attended by the palliative care team, members of the inpatient nursing team (who cover the palliative care ward when the palliative care team are out on visits and overnight) and the nursing superintendent. The team engaged well and were enthusiastic.

We were also asked to attend the weekly multi-disciplinary team (MDT) meeting held on a Saturday to offer education specifically for palliative care team and to feedback on our observations in practice. No medical staff were in attendance. Based on our observations, involvement in clinical discussions and review of clinical documentation a session was developed and delivered involving a full 'top to toe' assessment and review for each patient on each visit at home/outpatient based on St Columba's Hospice home visits. Within this session we introduced St Columba's Hospice pain assessment tool as a means to improve pain assessment and evaluation of interventions. We introduced the team to the Scottish palliative care guidelines as a point of reference and educational support acknowledging the range of drugs not available to them. This very interactive session allowed us to revisit any insights we had offered the team throughout the week in terms of excellent practice and suggestions for developing practice.

#### **The main points arising from the discussions were:**

- top to toe assessment on each visit or encounter
- recording of all assessments, plans of care and evaluations/outcomes (whether by phone or face to face)
- when more than one pain present the importance of assessing and recording each pain separately
- the difference between incident pain, breakthrough pain and neuropathic pain
- the potential for the use of morphine prior to painful procedures such as dressing changes (incident pain)
- encourage patients who persistently have a high pain score despite regular analgesia to use a breakthrough dose of analgesia
- investigate the availability of diclofenac PR
- use of pregablin for neuropathic pain (available to the team)
- assessment and management of depression – differentiating sadness from depression
- use of the Scottish palliative guidelines (pocket version/mobile app/online version) as a point of reference

The team wished to adopt St Columba's Hospice pain assessment tool (see appendix 1) and asked for help in developing new documentation which would support a plan of action and evaluation for community patients as described in the top to toe assessment (see appendix 2).

Through our second week we developed and refined the plan of care and supported its use in clinical practice, however as time was limited this is one area that would require to be further supported.

As no doctor attended the MDT meeting, a session was arranged to talk through our experience with the palliative care team. This session was attended by Dr Toni and Dr Sheba along with Sarjo. This allowed discussion around the complexities of managing patients and families with the available medications.

What was evident throughout our ten day period was the richness of the community spirit and support gained through shared Christian values across the Hospital as a whole. This was also reflected in the palliative care team and there was a sense of peace and calm gained through joint worship.

### **Our learning**

This remarkable team pull together to deliver holistic person centred palliative care with a real 'can do' attitude with limited resources.

When either out on home visits or when caring for people on an inpatient basis all members of the team become involved in ensuring that the needs of the patient and family are considered. For example when out on a home visit the registered nurse might spend time assessing the patient, the driver maybe having a supportive conversation with children or other family members and the nursing assistant be teaching a family member to make tomato soup for the patient to eat. No interaction or visit seemed rushed, the team often would join the patient and family in having a cup of chai which built and strengthened relationships. This valuable time allowed for questions or concerns to be raised which had not been voiced earlier. A case study illustrating their work care can be seen in appendix 1.

When a patient is approaching last hours of life and the period following a death all care is open and transparent. We witnessed a young man, being cared for after death outside in the hospital grounds, with a great deal of compassion, respect and dignity. The family were all around and about. As it was the families wish and cultural norm to take the deceased home and they had no means of doing this, the team drove this young man and family members in the patient transport ambulance. They helped 'lay him out' in a coffin built that morning by his father. The team went on to spend time in the family home joining in the after death rituals. We were privileged to be included in this.



## Recommendations

To continue to support this remarkable team in the valuable work that they do by:

- remote support via email, in the first instance, to offer guidance in the completion of the new documentation and pain assessment tool
- consider a return visit in the near future to (possibly November/December):
  - maintain and strengthen relationships
  - support the use of the pain assessment tool in clinical practice
  - support the use of the new community documentation in practice
  - further discuss the use of alternative medications and routes
  - implement the use of the Graseby MS26 syringe driver for palliative care in-patient use (see appendix 3)
  - investigate and develop remote support to include video calls between specialist nurses and medical staff from both sides for shared learning
- further visit next year (possibly April) to reinforce learning, evaluate work to date and establish new areas for development including consideration of the introduction of a reflective framework to promote MDT working/support
- To consider the relevance of our learning in relation to specialist palliative care in Scotland by:
  - Creating forums for discussing the openness regarding death and dying witnessed in India
  - Creating opportunities for considering the question “have we become too medicalised”?

## Case study

Sunitha's dressing change:

Once a fortnight the community team visited Sunitha at home to assess her symptoms and change her dressing to her fungating breast wound. In-between times her dressing is changed by her family.

At the start of the visit, before moving on to a more formal assessment, time was spent chatting to the Sunitha and her family who all lived in the small shelter. There was a lovely sense of warmth and ease between the team, Sunitha and her family.

During this visit Ribica (RN training in palliative care) performed the dressing change with guidance and assistance from her mentor and lead nurse in the palliative care team, Sarjo. This difficult dressing was undertaken with time, patience, skill and empathy. Throughout the procedure all family members were present as were all team members. It was natural and easy for all to be present. As Ribica took time to soak away the old dressing from the wound, Sarjo sat next to Sunitha and fanned away the flies. During the dressing change Sunitha appeared pained although later when asked about it denied any pain during that dressing change. She did however admit to having pain when family members performed the dressing change.

Metronidazole tablets were crushed in-between paper and two stones then sprinkled directly onto the wound to manage unpleasant odour. Gauge swabs were then placed gently on top and secured with tape.



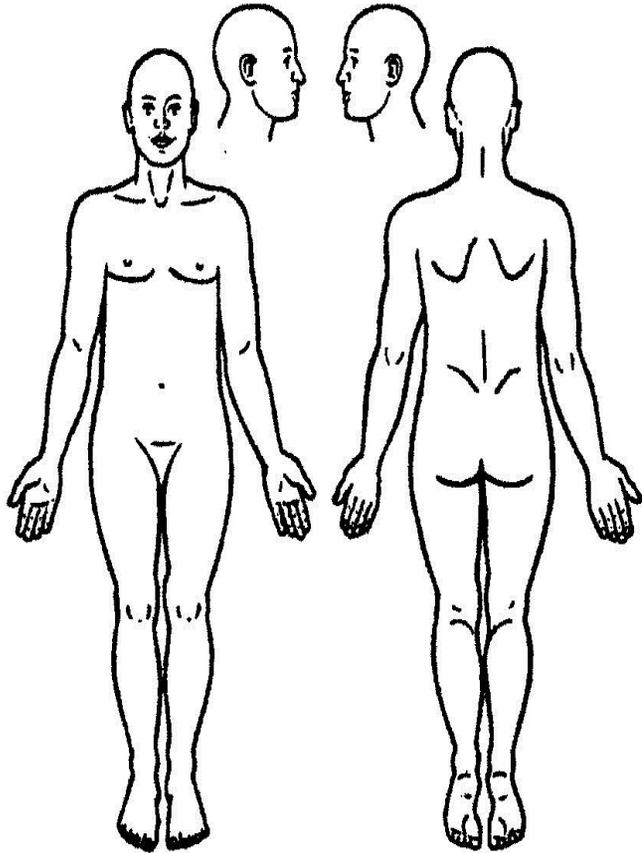
Conversation moved onto the health of a sick baby, Sarjo ensured that the baby was okay and had a planned hospital appointment that day before we left.

There was much to witness in terms of good practice. We were able to compliment the team on the rapport between them and Sunitha and family, assessment skills and skills in relation to the dressing change. We were able to advice regarding the possibility of using analgesic prior to painful dressing changes.



**To be completed by medical staff within the first 24 hours if appropriate. To be kept with Drug Kardex throughout admission. Further information regarding pain (existing or new) can be added at any time.**

**(Record if any areas of the assessment are not appropriate)**



- Identify site of pain on the body map.
- Has site of pain been examined? Yes  No  N/A
- Is pain radiating? Yes  No  (If yes, record on body map)

|                                                                                                                         | Pain A | Pain B | Pain C |
|-------------------------------------------------------------------------------------------------------------------------|--------|--------|--------|
| <b>Pain Score Now</b>                                                                                                   |        |        |        |
| <b>Worst Pain</b>                                                                                                       |        |        |        |
| <b>Pain Description</b><br>(including the duration of episode of pain, type of pain)                                    |        |        |        |
| <b>How long have you had a problem with pain</b><br>(including when pain started)                                       |        |        |        |
| <b>Possible causes of pain</b>                                                                                          |        |        |        |
| <b>Aggravating Factors</b>                                                                                              |        |        |        |
| <b>What pharmacological interventions worked?</b>                                                                       |        |        |        |
| <b>What non pharmacological interventions worked?</b>                                                                   |        |        |        |
| <b>Spiritual aspects of pain</b>                                                                                        |        |        |        |
| <b>Psychological aspects of Pain</b>                                                                                    |        |        |        |
| <b>Social aspects of pain</b>                                                                                           |        |        |        |
| <b>Comments from family when the patient is unable to tell us due to cognitive impairment or level of consciousness</b> |        |        |        |

|       |       |       |
|-------|-------|-------|
| Date: | Date: | Date: |
| Sign: | Sign: | Sign: |

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### Daily Pain Assessments

Name:

DOB:

Complete on day of admission and then daily.

If scores of no pain recorded for 5 days consecutively consider discontinuing daily recording.

If pain develops during admission or new pain site identified ensure initial pain assessment is commenced/updated.

|                 |    |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|-----------------|----|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| Date            |    |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| <b>Severe</b>   | 10 |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|                 | 9  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|                 | 8  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|                 | 7  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|                 | 6  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| <b>Moderate</b> | 5  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|                 | 4  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| <b>Mild</b>     | 3  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|                 | 2  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|                 | 1  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| <b>No Pain</b>  | 0  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |

If a pain score cannot be obtained from the patient please indicate a doctor/nurse assessed pain score below.

|                 |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|-----------------|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| <b>Severe</b>   |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| <b>Moderate</b> |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| <b>Mild</b>     |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| <b>No Pain</b>  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |

|                                                            |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|------------------------------------------------------------|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| <b>Further information in progress Notes (please tick)</b> |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| <b>Signature</b>                                           |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |

|                           |                   |                          |                   |
|---------------------------|-------------------|--------------------------|-------------------|
| <b>Date discontinued:</b> | <b>Signature:</b> | <b>Date recommenced:</b> | <b>Signature:</b> |
|---------------------------|-------------------|--------------------------|-------------------|



**Harriet Benson Mission Hospital: Lalitpur**  
**Community Palliative Care Team: HOME VISIT FORM**

**Appendix 3**

**Top to Toe Assessment and Plan of Care**

|                                                                                                           |                                                                                                                   |                                                          |
|-----------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|
| <b>Patients Name:</b> Shahid Rapour<br><b>Village:</b> Nowhere<br><b>Date:</b> 15/3/2017 <b>Time:</b> 1pm | <b>Home Visit/ Telephone Consultation:</b><br><i>Please circle</i><br><b>Date of next visit/review:</b> 18/3/2017 | <b>Professional/s involved:</b><br><br><b>Signature:</b> |
|-----------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|

*Tick all relevant boxes*

Depression     Mouth     Breathing     Eating/Drinking     Nausea/Vomiting     Weight loss     Bladder     Bowels     Skin/wound   
 Swelling/Oedema     Mobility/Self Care     Difficulty Sleeping     Drowsiness     Delirium/Confusion     Fatigue     Fever     Psychosocial   
 Spiritual     Pain  (If pained also see separate pain assessment tool)    Family concerns     Other

**Initial overall impression:** Shahid up sitting on arrival, quiet and no initial eye contact. Appeared low in mood. Wife welcomed us at the door and looked tired. Othe family members present.

| Problem/Symptom:            | Assessment:                                                                                                                                                                                | Plan of Care:                                                                                                                                                                                                                                | Evaluation:                                                                                                                                         |
|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|
| Depression and psychosocial | When suggested he looked sad, he admitted he was and that he was feeling sad at leaving his wife and family behind, worried about how they will cope without him – worried about finances. | Time spent listening and exploring concerns. Encouraged to share his concerns with his wife and wider family, Shahid is going to try and do this.<br><br>Consider mood on next visit and consider anti-depressant therapy if no improvement. | <p align="center"><b>Date:</b>                      <b>Time:</b></p> <p align="center"><b>Home visit/Telephone Consultation (please circle)</b></p> |
| Mouth & eating and drinking | Shahid reports a painful moth and pain on swallowing. On examination oral thrush evident – possibly affecting throat and swallow.                                                          | Commenced fluconazole 50mgs and advised on keeping mouth clean after eating.<br><br>Encourage soft diet, small portions                                                                                                                      | <p align="center"><b>Date:</b>                      <b>Time:</b></p> <p align="center"><b>Home visit/Telephone Consultation (please circle)</b></p> |
| Weight loss                 | As before appears to continue to lose weight. See above assessment for mouth care/eating and drinking                                                                                      | As above and advised to change position frequently to avoid pressure sores developing                                                                                                                                                        | <p align="center"><b>Date:</b>                      <b>Time:</b></p> <p align="center"><b>Home visit/Telephone Consultation (please circle)</b></p> |

| Problem/Symptom: | Assessment:                                                                                                                                                                                                                       | Plan of Care:                                                                                                                                                                                                                                         | Evaluation:                                                                                  |
|------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------|
| Wound            | Fungating lesion from lymph node – neck. Right side.<br>Aprox. 2 inches by inches<br>Malodorous<br><br>Pained on dressing change                                                                                                  | Cleanse with n. saline, apply metronidazole tablets (crushed) and cover with gauze swabs.<br><br>Family will continue with daily dressings<br><br>Give PRN 5 mgs morphine 20-30mins prior to dressing change                                          | Date:                      Time:<br><b>Home visit/Telephone Consultation (please circle)</b> |
| Pain             | Pain on dressing change (8/10)<br><br>Currently on 5 mgs regular morphine – reporting shooting pain from neck into right side of head – described burning sensation has used break through morphine but has not found it helpful. | Dressing change – see above<br><br>Re nerve pain - following telephone call with Doctor Tony – commenced on amitriptyline 10mgs at night time<br><br>Phone in 3 days to evaluate effectiveness of amitriptyline and morphine prior to dressing change | Date:                      Time:<br><b>Home visit/Telephone Consultation (please circle)</b> |
|                  |                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                       | Date:                      Time:<br><b>Home visit/Telephone Consultation (please circle)</b> |
|                  |                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                       | Date:                      Time:<br><b>Home visit/Telephone Consultation (please circle)</b> |
|                  |                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                       | Date:                      Time:<br><b>Home visit/Telephone Consultation (please circle)</b> |

## References

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