



**An update report for The Alfie Gough Trust
Complementary Therapy Programme
2017/2018**



**GREAT
ORMOND
STREET
HOSPITAL
CHARITY**

Thank you

We are delighted to provide The Alfie Gough Trust with this update report, which has been prepared by Jenni Hallman and includes information and updates on the Complementary Therapy Service from the past year.

Thanks to your generous support, the Complementary Therapy Service at Great Ormond Street Hospital continues to go from strength to strength. We very much hope you enjoy reading about this important work and the patients and families it is supporting.

On behalf of everyone here at the charity and the patients, their families and the staff at the hospital thank you for your continued support – it really is very much appreciated.



Introduction

The Complementary Therapy Service at Great Ormond Street Hospital is now entering its eighth year.

1. Service profile

The service is comprised of a Complementary Therapy Nurse Specialist (CTNS) who provides relaxation and massage (primarily using the "M" technique¹) on Great Ormond Street Hospital's oncology wards. Children are seen either at their hospital bed or, if they are well enough and infection free, in the complementary therapy room (see appendix 1).

Sessions can last from 20 minutes to over an hour depending on the needs of the child and their family. Some children and their families use the opportunity to talk about their treatment, whereas for others it is a time for quiet and relaxation. Some parents take the opportunity of their child having a massage session to take time off the ward and other families arrange their sessions around other key events like physiotherapy so as to relax afterwards.

The Alfie Gough Trust has generously supported the service from March 2015. Since January 2018 the number of hours worked has reduced from 0.85wte to 0.77wte. The number of clinical nursing shifts has therefore increased from 0.15 to 0.23wte.

2. Referrals

The CTNS continues to meet all children and families that are nursed on Lion, Elephant and Giraffe wards. The service is introduced to families at the time of, or shortly after, admission. Most children are seen as a result of this personal introduction, with the second most common referral method being word of mouth from parents or from the children themselves.

A number of referrals are received from physiotherapists, occupational therapists, advanced nurse practitioners, doctors and consultants based on the oncology wards. Ward nurses also continue to regularly update and refer to the CTNS.

There have been 10 referrals from non-cancer wards, a decrease from 2016-2017, but there has been an increase in the number of clinical trial patients seen - rising from 1 to 11. Children accessing clinical trials have often been in hospital for extended periods of time and therefore the emotional and physical needs of both the child and family are often increased, meaning the amount of time spent with these children tends to be longer.

Referrals have been received from a range of specialities and from varied members of the multi-disciplinary team, as shown in the table below (fig 1).

¹ The "M" technique is a structured, gentle form of massage created by Dr Jane Buckle, which is suitable for fragile and critically unwell patients.

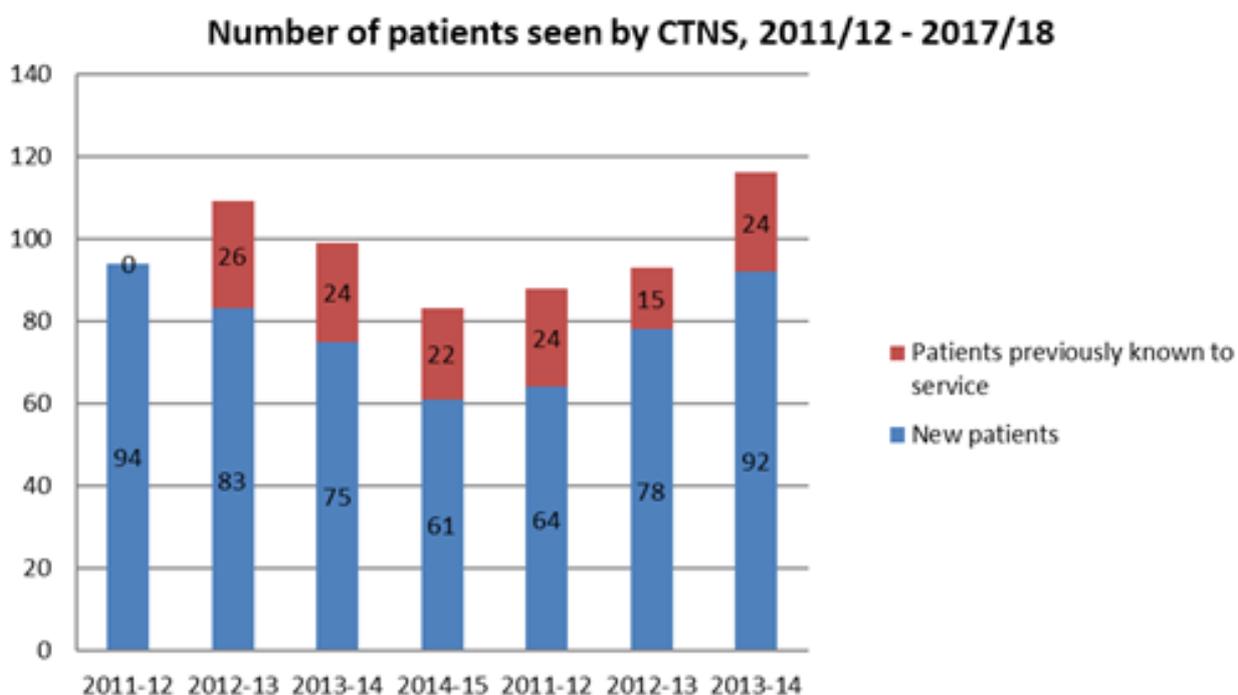
Speciality	Role of Referrer	Number referrals	Number of times seen
Respiratory	Play Specialist/Physio	3	11
Metabolic	Play Specialist/Physio	2	6
CICU	Family Liaison/Physio	2	7
Neurology	Nurse	2	7
Trial Patient	Consultant Nurse Specialist/Play Specialist	11	105
Orthopaedic	Consultant Nurse Specialist	1	33

Fig 1: non-cancer referrals to CTNS, 2017/18

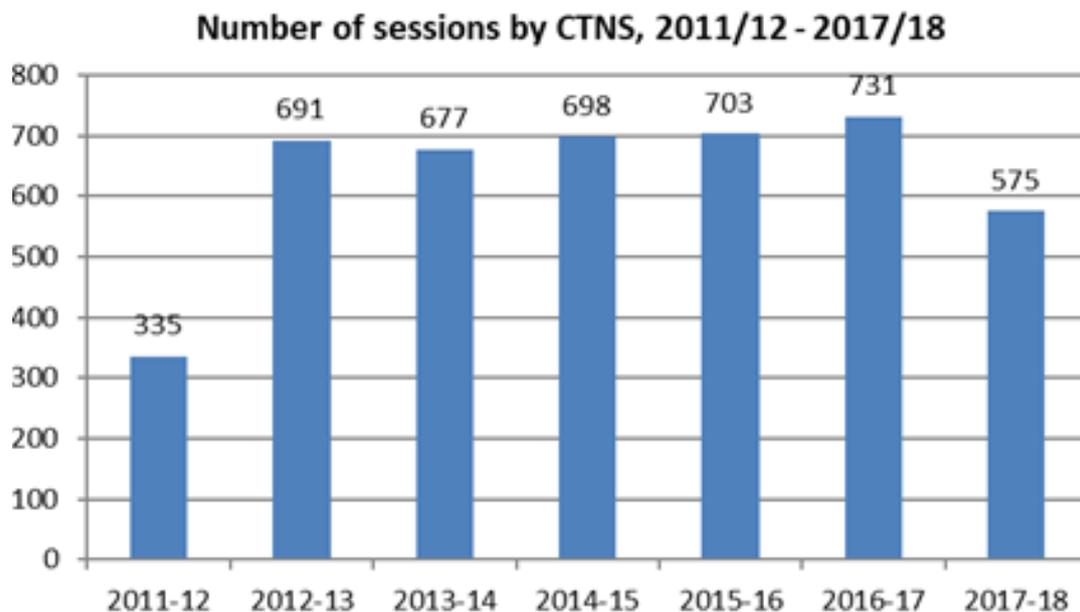
The previous year saw a large number of referrals from the Cardiac Intensive Care Unit (CICU). These have slightly reduced this year although the CTNS is still providing group baby massage sessions. The Respiratory and Metabolic Wards have shown a recent interest for some of their long-term patients and the play worker from the ward is hoping to complete a baby massage course later in the year, so she can further support parents and carers.

3. Activity and caseload

The number of patients seen by the CTNS has increased slightly compared to the last two years and generally remains stable. There has been an increase in the number of new patients seen, although it should be noted that generally patients seen in other specialities are seen in groups to maximise time efficiency.



The number of massage sessions has decreased to 575. This is likely to be due partly to the increased length of time spent with each child and family, and partly to a reduction in hours worked by the CTNS since January 2018.



Results from the previous three years have noted that the length of session have increased due to the complex and increasing needs of the patients. Extra time is often required to position patients who have complex needs and ensure their comfort throughout the massage session. The parents of these patients are also often in need of more emotional support which can be offered after the session. For these children and families sessions can last between 40 – 90 minutes.

The previous years have seen a slight increase in the number of palliative care patients who have chosen the hospital for their place of care; sessions for palliative patients, especially those who have previously used the service, are understandably longer in duration in terms of both the massage given and support provided by the CTNS to the child and family. A total of nine palliative care patients have been seen this year, resulting in 49 overall sessions. The actual number of sessions is difficult to accurately measure as a number of the children were known to the service prior to them requiring palliative care – there may be some overlap in the number of sessions before and after the patient transitions to palliative care.

In addition to the above, the CTNS continues to co-ordinate volunteers who provide massage for parents. This currently covers three wards. There are currently two volunteers in place, working one evening each per week and seeing an average of six to eight parents per week.

We can also confirm that of the patients treated, the CTNS has worked with 10 children undergoing treatment for neuroblastoma. This equated to 77 separate sessions throughout 2017/2018.

4. Educational activities and staff training

All staff members on the oncology wards are aware of the role of the CTNS. Rotation staff (newly qualified nurses who work for eight months on one of the oncology wards before going to another speciality) and new starters are met during their induction period to be informed of the role. Student nurses have the opportunity to spend a few hours with the CTNS during their ward placements. New doctors are informally made aware of the service.

Further formal teaching sessions were delivered for nurses on the oncology and the pain management degree pathways. For this financial year this has totalled three hours face-to-face teaching on each course. In addition to the above the CTNS has also carried out relaxation sessions for internal and external candidates on the paediatric palliative care foundation course three times this year.

The CTNS also undertook a two-day Diploma course in Reflexology provided by the Therapy Training School. The principles of Reflexology have since been incorporated into the M Technique massage for some patients and basic techniques taught to parents and carers.

5. Research, publications and conferences

Work has begun or continued on the following projects:

- The CTNS has completed a chapter for the Great Ormond Street Hospital nursing manual on complementary therapies; this is now undergoing a final edit. The publication of this updated version has been delayed and is expected in 2019.
- "M Technique" article – awaiting completion.
- Consultancy advice for CCLG booklet – information leaflet for families of a child with cancer and the use of complementary therapies.

6. Service developments

6.1. Patient survey

The CTNS has been asking children and families to complete a survey via Survey Monkey. This has been registered as an Audit and asks the question "Does massage for Oncology patients improve their overall hospital experience?" (Audit No: 1967). The survey is quick and easy to complete, with child-friendly questions and emojis. Full results are found in appendix 2, but in summary:

- | |
|---|
| <ul style="list-style-type: none">• 62% of responses showed an <i>improvement in mood after the massage</i>.<ul style="list-style-type: none">○ The remaining 38% reported no change in mood; where this was the case 78% reported their mood as already <i>Very Happy, Happy</i> or <i>OK</i>. |
| <ul style="list-style-type: none">• Of those children who reported pain before the massage, 95% of responses showed an <i>improvement in pain after massage</i>.<ul style="list-style-type: none">○ The remaining participants reported no pain either before or after the massage. |
| <ul style="list-style-type: none">• 94% of responses showed an <i>improvement in sleep after the massage</i>.<ul style="list-style-type: none">○ Before the massage, children reported an average sleep score of 2/10; after the massage this increased to an average sleep score of 6/10. |
| <ul style="list-style-type: none">• 93% of children reported that <i>having a massage helped them to feel 'a lot' better</i> when they are in hospital.<ul style="list-style-type: none">○ The remaining 7% reported that the massage helped them to feel a <i>little bit</i> better when they were in hospital. |

6.2. Information sheets

All information sheets have been updated as required.

6.3. Baby massage sessions

Baby massage teaching sessions have been held on CICU, each session lasting 30-40 minutes with an average attendance of three to four parents.

7. Personal development

The CTNS has made the difficult decision to resign from this post and will commence new employment in a different Trust in May 2018. It is hoped that the service will continue at Great Ormond Street Hospital and a number of oncology nurses have expressed an interest. The CTNS hopes in some way to be involved in supporting her successor when they transition into the role.

8. Service budget

Consumables are paid for from ward funds and the total expenditure in 2017/18 was £250, this is approximately £200 less than previous years. Previously the largest spend was on the purchase of heat packs. Due to infection control the type of heat packs used are no longer advised on the ward and therefore will no longer be purchased.

9. Outcomes and feedback

There continues to be positive feedback from the children and families who access the service. Many feel that the sessions are something to look forward to and that they help to structure their day. Children have reported that their pain has felt better, they feel happier and that they have slept better.

Patient feedback

The creams smell really nice. I like to massage my mummy's hands with the left over cream.

5 year old girl with NBL

Massage helps when my legs ache & then I can get up and play more.

8 year old boy with ALL

The Complementary Therapy Nurse Specialist is nice to talk to and always makes me feel better. Sometimes it makes me really sleepy, I wish I could have a massage every day.

9 year old girl with AML

Parent feedback

A wonderful service which has helped us all to relax when our daughter felt poorly. This worked really well alongside her medical treatment and rehabilitation which is so important to us all. The Complementary Therapy Nurse has been so helpful, always going the extra mile and very patient with answering all our questions. We can't thank you enough.

Mum of 8 year girl with relapsed disease

Thank you so much for making my daughter smile and giving us all something to look forward to.

Mum of 7 year old girl with NBL

Amazing service, it has helped our son so much. He always asks for the CTNS and always feels better afterwards. It's nice that he has someone to talk to, I trust the CTNS completely as she is a nurse and I know my son feels the same.

Mum of 12 year old boy with relapsed disease

Staff feedback

This has been an invaluable help for patient A & really helped lift her mood. We are very thankful that the Complementary Therapy Nurse Specialist was able to see her & provide this service. This should be available to all children in Great Ormond Street Hospital regardless of their diagnosis.

Staff member on orthopaedic ward

All the children and families ask for the CTNS, she makes such a difference to them and it is lovely for us to see the children relaxing and to know that the parents have had some much-needed TLC too.

Staff Nurse on Lion Ward

10. Conclusion

The Complementary Therapy Service continues to grow and there continues to be positive feedback from parents, children and members of the multi-disciplinary team. Massage has become an important part of the in-patient experience for children on the oncology wards.

Jenni has been privileged to initiate this service at Great Ormond Street Hospital and will always remain eternally grateful to have been given this opportunity. It is hoped that the service will continue to grow and to flourish when the new CTNS is in position.

Appendix 1: Complementary Therapy Room

Complementary Therapy Room situated on Lion Ward. Funded by The Sunflower Jam



Cloud lightbox on ceiling



Therapy couch and calming sea/sunset window blind.

Appendix 2: Report on service evaluation survey

Does Massage for Oncology Patients Improve Their Overall Hospital Experience

18 April 2018

Jenni Hallman, Complementary Therapy Nurse Specialist; Nicole Douglas, Clinical Governance and Audit Assistant

Background

The nurse-led massage service has been in place on the oncology wards at Great Ormond Street Hospital since 2011. A service evaluation conducted in 2013 showed that massage positively impacted children's hospital experiences and on-going verbal feedback supports this. Many children can spend weeks, if not months, in isolation undergoing painful procedures and experiencing side effects of treatment. Reviewing the literature, we can see that children often have heightened anxiety when hospitalised and that massage is seen as calming and soothing, as opposed to conventional medicine which is often perceived as rushed and enforced, (Coyne 2006, Wood and Finlay 2011).

Aim

To evaluate the impact of massage offered to children with cancer in relation to pain, sleep and relaxation and to guide future research in this area.

Methodology

Children were asked to complete an online survey before and after a massage and self-report their mood, levels of pain and level of sleepiness. Children were also asked to complete a final online questionnaire evaluating their entire experience of receiving complementary massage therapy. A total of 23 children participated in this evaluation; children completed each cycle (both before and after massage) between one and four times. The final survey was completed by 14 children.

Key Highlights

After receiving a massage:

- **62%** (n29/47) of responses showed an **improvement in mood after the massage**.
 - The remaining 38% (n18/47) reported no change in mood; where this was the case 78% reported their mood as Very Happy (n7/18), Happy (n7/18) or OK (n4/18).
- **95%** (n19/20) of responses showed an **improvement in pain after massage**.
 - The remaining 27 participants reported no pain both before and after the massage
 - Before the massage, participants reported an average pain score of 2/10; after the massage, participants reported an average pain score of 1/10.
- **94%** (n44/47) of responses showed an **improvement in sleep after the massage**.
 - Before the massage, participants reported an average sleep score of 2/10; after the massage this increased to an average sleep score of 6/10.
- **93%** (n13/14) of participants reported that **having a massage helped them to feel 'A lot' better** when they are in hospital
 - The remaining 7% (n1/14) reported that the massage helped them to feel A little bit better when they were in hospital.

Summary of Qualitative Feedback

Patient feedback

The word cloud below represents the key themes identified from responses when children were asked what they valued most about having a massage. The larger the word the more prominent the theme.

Improves mood Improves pain Improves mobility and play
Aromatherapy Positive staff engagement
Improves sleep Pleasant experience

What do you value the most about being able to have a massage?
<i>That it will make my legs better & make me feel sleepy</i>
<i>Makes my legs feel better</i>
<i>The creams smell nice. I like to massage my mummy's hands with the leftover cream</i>
<i>It helped when my legs ached & meant that I could get up and play more</i>
<i>It makes me sleepy - the Complementary Therapy Nurse Specialist is nice to talk too</i>
<i>I love the creams and the room and the Complementary Therapy Nurse Specialist is really nice and fun too</i>
<i>It's nice</i>
<i>The nice smelling creams & having a nice sleep</i>
<i>I like the creams and talking to the Complementary Therapy Nurse Specialist</i>
<i>Makes me feel better when I have pain and helps me to rest</i>
<i>Something to look forward to & it helps my back feel a bit better</i>
<i>It makes me feel better</i>
<i>Relaxing in the room with the twinkly lights & fluffy blankets & choosing the creams.</i>
<i>I like the creams and how it makes me feel sleepy</i>

Parent/Carer feedback

For Parents: Is there anything you would like to tell us about the complementary therapy that your child has received?

Amazing service. It helps him so much, he always asks for the Complementary Therapy Nurse Specialist & always feels better afterwards. Nice that he has someone to talk to, I trust the Complementary Therapy Nurse Specialist completely as she is a nurse & I know my son feels the same. Thank you x

Nice and relaxing, especially at the moment when she is feeling quite tearful

It is very good & helps a lot. All children in the hospital should have been this

A wonderful service which has helped us all to relax on days when our daughter has felt poorly. Works wonderfully alongside her medical care and her rehabilitation, which is so important to us all. The Complementary Therapy Nurse Specialist has also been so very helpful going the extra mile and very patient with answering all our questions. Thank you for all that you have done for us.

Lovely service we will miss it when we go to Oxford. The Complementary Therapy Nurse Specialist has been a great support to both of us. Thank you

A lovely service and something we didn't expect but now really look forward too. It helped through some really tricky stages of our treatment and is something that we can now look back on with happy memories.

Really wonderful. We were offered this as a bit of a special case as the Complementary Therapy Nurse Specialist doesn't work on the cardiac unit but I think all children whatever their condition would benefit from this. Been a great help and taught me a lot. Thank you very much from the bottom of our hearts for the good memories you have given us.

Wonderful. Just wonderful. Thank you

Thank you for this lovely service; always nice to look forward to and the Complementary Therapy Nurse Specialist always makes us feel like we are the most important people in the world. A true gift.

Very good, wish we could have this every day.

No parents, staff nurse comment: This has been an invaluable help for patient A & really helped lift her mood. We are very thankful that the Complementary Therapy Nurse Specialist was able to see her & provide this service. This should be available to all children in GOSH regardless of their diagnosis

Its brilliant, wish we could take the Complementary Therapy Nurse Specialist home she works wonders.

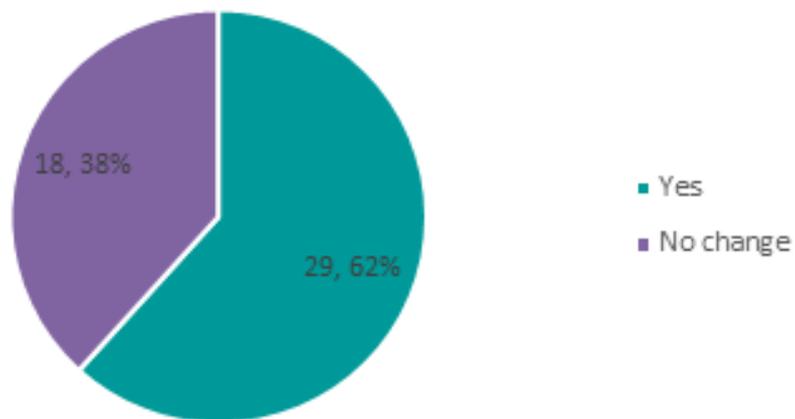
This has been really helpful for relaxing us as a whole family

Thank you so much for making my daughter and me smile and giving something to look forward to

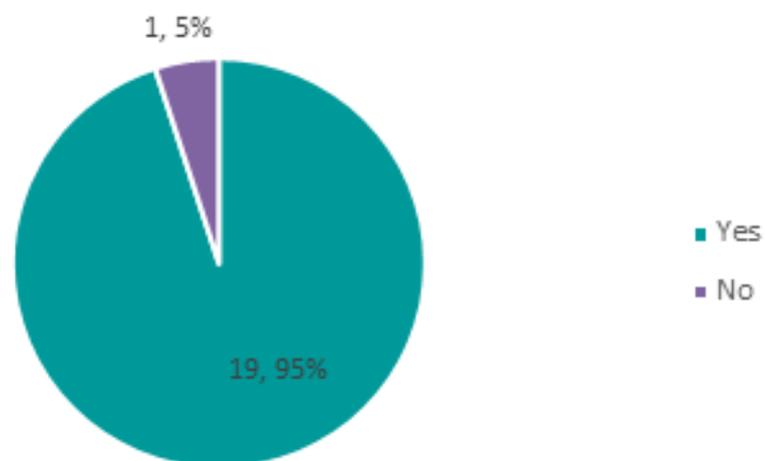
Full results

Quantitative results:

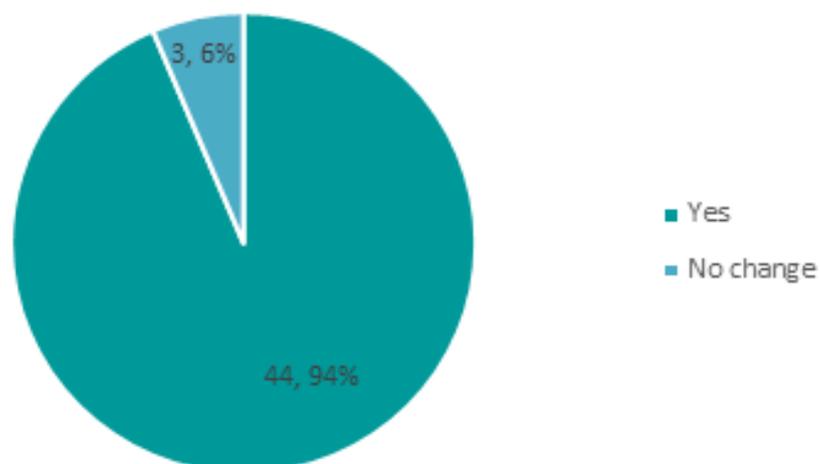
Was there an improvement in Mood after receiving a massage?



Was there an improvement in pain after the massage?

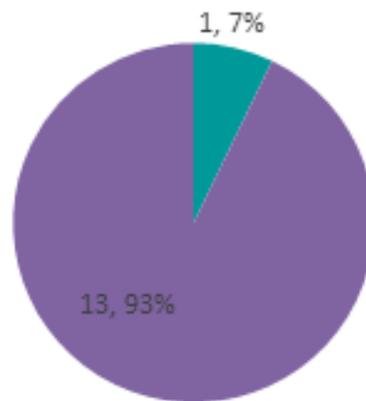


Was there an improvement in sleep after the massage?

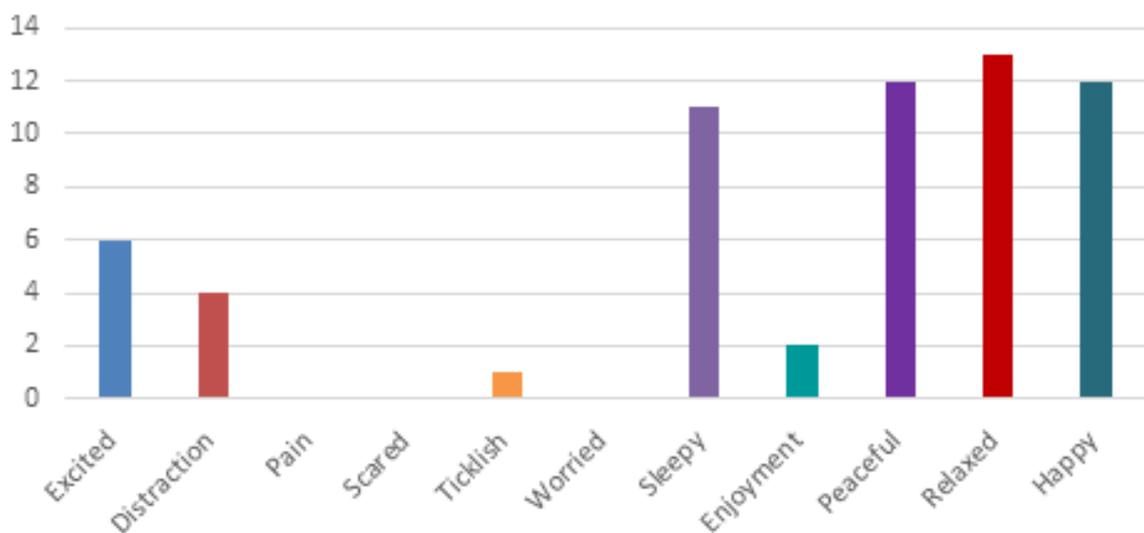


Does having a massage help you to feel better when you are in hospital

■ A little bit ■ A lot ■ Not at all



When you think about having a massage, what words describe how you feel?



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