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SUPPORTED: THE DEVELOPMENT OF AN ABDOMINAL SUPPORT GARMENT FOR PEOPLE WITH ASCITES

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Background Ascites, a palliative symptom, is the build-up of large volumes of fluid in the peritoneal cavity which is drained at around five litres. If an indwelling catheter isn't possible then living with large volumes of fluid which are intermittently drained, is very uncomfortable. Earlier research showed that an abdominal support garment improved discomfort and provided support to their large distended abdomens (Preston 2004). However, the garment was too warm and also 'rode up' making it difficult to wear especially in warmer weather.

Aim To assess the acceptability of a support garment for use with people with ascites.

Methods Five prototypes for a support garment using a range of materials to offer abdominal support were developed with the company Jobskin. The ongoing study with eight participants with ascites (alcohol related liver disease and malignancy) will assess wear-ability and support requirements including an assessment of comfort, ease of putting on/off, mobility and acceptability. The garment, shaped like cycling shorts, can be made in a range of sizes and colours.

Results A garment was developed using five sections offering different types of pressurised support including a main abdominal area which allows for support but can significantly increase to allow for abdominal growth. The support garment supported an increase in abdominal girth from 70 cm to 110 cm in the initial participant yet remained comfortable. Early results have had it described as 'invaluable' by one doctor at the end of life of a patient to help her get in and out of bed when drainage was no longer an option.

Interpretation and conclusions A support garment has been created which can allow for increased abdominal girth yet provide abdominal support. Early indications show it is very acceptable, improves discomfort and offers the support required.

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'IN CONTROL FOR WHAT MATTERS' LIVING WITH BREATHLESSNESS AND LOW ENERGY: VIDEO RESOURCES FOR PATIENTS

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Background 2014 Staff Conference "Be Inspired" "An increasing ageing population... Unmet needs... Life limiting conditions, Limited resources". The message heard 'Become preventive and proactive'.

Breathlessness patients who achieve self-management breath control, typically say "I am overcoming my fears and worries", "... Given me back my life".

Our patients have not stopped living and the timely access and mastery of self-management are key but do not happen only when in the presence of a health professional.

Aims How can the existing resources reach these unmet palliative care needs with empowerment and enablement?

The early referral is the most proactive "... Exercise and acquiring anxiety reduction techniques is most useful early". What will enable the early referral?

Patients fear coming to the Hospice "first thought... a place people go to die". What resources will reduce these fears?

Patient empowerment is necessary for success of the interventions. What resources are needed for mastery and how to make them accessible?

Method The physiotherapy team have produced short video tutorials with in-house resources for patients to use at home. The first one explains the breathlessness spiral of fears, avoidance and deconditioning, introducing upward spiral of gaining control and power. The rest of the videos have the various techniques taught in the outpatient session; thus supporting practice by the patient at home following their appointment.

Results Currently the videos are in CD format with patient feed-back currently being collected. The hospice's next step is the development of a "Patient and Carer Portal" with direct links to the electronic patient record; wherever they are located, patients will be able to access their 'prescribed' videos, through the Portal.

This pilot of self-help videos will be tested against measureable criteria establishing

- · cost effectiveness
- accessibility
- compliance
- patient outcomes and satisfaction,
- impact on resources.

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HOSPICE BASED DAY CASE BLOOD TRANSFUSIONS ENCOURAGE EARLIER REFERRAL INTO PALLIATIVE CARE SERVICES

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Background Anaemia is widely prevalent in palliative care patients, and is often multifactorial. Effects of anaemia can include fatigue, breathlessness, or even angina. Palliative care patients benefit from treatment of their anaemia, and day case blood transfusions help to avoid inpatient admissions.

Aims Our day case blood transfusion service was set up in 2012. Initial review of this service indicated that offering a blood transfusion within a hospice setting encouraged earlier referral into palliative care services. On this basis we explored the options for increasing our blood transfusion referrals. This allows patients to benefit from the diversity of therapies and services that the hospice can offer at an earlier stage in their illness, and reduces pressure on hospital services.

Method Since July 2015, in conjunction with our local acute NHS trust haematology unit, we have significantly increased our referrals to the blood transfusion service within our hospice. To enable us to do this we installed a satellite blood fridge in the hospice, and now run a thriving day case blood transfusion service.

Results At present, we can accommodate 14 transfusion appointments per week (offering packed red cells and platelet transfusions) and we have seen a significant increase in appointments in this last year.

Year (April-March)	Number of transfusion appointments
2012 – 2013	35
2013 - 2014	72
2014 – 2015	81
2015 – 2016	293

Conclusion Coupled to the significant increase in referral numbers to our service there has been a noticeable increase in the number of patients referred with haematological diagnoses. Many require multiple recurrent transfusions over many months which allows a natural progression from active treatment into palliative services, within an environment which is well equipped to support them as their illness deteriorates. Our patient feedback shows we are running an excellent service for our patients, in a setting they enjoy.

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ASSESSING PAIN IN CHILDREN WHO ARE NON VERBAL OR COGNITIVELY IMPAIRED

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Barriers to pain management in infants and children are vast and include inaccuracies regarding pathological mechanisms of pain and deficient knowledge of methods of assessing pain (Srouji et al., 2010). Despite recent advances in our understanding of children's pain, difficulties lie in distinguishing pain from other sources such as anxiety and stress (Voepel-Lewis 2011). The unique challengers assessing pain in children are age, development, communication skills and past experiences of pain (Srouji et al., 2010). These challengers are increased when there is varying levels of cognitive ability, and children with cognitive impairment are at greater risk of under treatment (Clen-Lim et al., 2012). The common problem is the inability to verbally selfreport their pain and the frequent exposure to pain due to association of disease pain and the high impact on quality of life (Massaro et al., 2013). Measurement of pain is essential and is assessed to determine the effectiveness of the treatments (Massaro et al., 2013). For children with communication difficulties a valid and reliable tool should always be used (Massaro et al., 2013). The Faces, Legs, Activity, Cry and Consolability (FLACC) behavioural tool developed by Merkel, Voepel-Lewis, Shayevitz, and Malviya (1997) was not originally designed for cognitively impaired children however has shown to be a valid and reliable tool in this population (Massaro et al., 2013).

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ENABLING PATIENTS TO SELF-MANAGE THEIR PAIN; A PILOT OF A MODIFIED PAIN MANAGEMENT **PROGRAMME**

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Background Despite WHO recommendations for the management of pain the prevalence in palliative patients remains between 62-86% and management remains primarily pharmacological. There is good evidence for the efficacy of Pain Management Programmes (PMP) based on cognitive behavioural principles for patients with chronic pain. They have been shown

to improve pain experience, mood, coping, and activity levels. Palliative patients are rarely eligible for inclusion on such programmes.

Aim

- To pilot and evaluate a holistic PMP tailored to the needs of palliative patients
- To reduce use of analgesics
- To introduce techniques for self-management of pain.

- Patients with a life-limiting illness, complex pain, a Pain Score greater than 5 and a Karnofsky Performance Scale greater than 50% were eligible for enrolment in the six week programme
- Patients were initially assessed by a palliative consultant and a pharmacist to optimise drug regimens
- The PMP used a multi-disciplinary rehabilitative approach introducing the Pain Toolkit, Mindfulness, Relaxation, Cognitive Behavioural Techniques and Seated Exercise
- Evaluation was by structured questionnaires, the Hospital Anxiety and Depression Scale (HADS) and Pain Scores.

- 18 patients met the inclusion criteria, nine patients agreed to take part, five patients completed the programme. Age range 32 to 74 years
- Patients reported moderate to severe anxiety and depression at the start. HADS scoring showed category improvement by
- Mindfulness and relaxation were rated as the most beneficial elements
- Patients reported group working supportive
- Pain scores did not change significantly but patients used less breakthrough medication
- Patients were able to employ techniques to self-manage pain.

Conclusion It can be difficult for palliative patients to attend a six- week programme; however for those who are well enough the pilot showed benefit, it improves pain self-management and reduces use of analgesics. Wider introduction of modified PMPs could be considered for palliative patients.

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USING ONE PAGE PROFILES TO IMPROVE PERSON CENTRED CARE ON THE INPATIENT UNIT (IPU)

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The Inpatient unit are constantly looking at the way in which we work and how we can improve and change practice. One of the current projects we are undertaking is based on person-centred care and One Page profiles.

A one page profile captures all the important information on a single sheet of paper under simple headings. We have produced our own one page profile and named it 'What is Important to You' the headings we are using are:

- How will decisions be made, who will be involved in this?
- What is important to me?
- How to support me and those I love
- What must happen?
- What must not happen?

One page profiles are a way of learning and supporting people to achieve things that are important to them. Even if someone is