

The evolution of the Newcastle CRESTA Fatigue Clinic: a unique NHS multidisciplinary approach to fatigue

Authors

Rebecca L Lambson¹,
Julia L Newton², Victoria
Strassheim³, Zoe M
Gotts⁴,
Vincent Deary⁵,
Katie L Hackett⁶



1 Medical Student, Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK.

2 Dean of Clinical Medicine, Professor of Ageing and Medicine and Honorary Consultant Physician, CRESTA Fatigue Clinic, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK, and Clinical Academic Office, Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK.

3 Specialist Physiotherapist, CRESTA Fatigue Clinic, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK.

4 Post Doctoral Research Associate, Faculty of Health and Life Sciences, Northumbria University, Newcastle upon Tyne, UK.

5 Health Psychologist and Senior Lecturer, CRESTA Fatigue Clinic, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK and Faculty of Health and Life Sciences, Northumbria University, Newcastle upon Tyne, UK.

6 Specialist Occupational Therapist and Arthritis Research UK AHP Training Fellow, CRESTA Fatigue Clinic, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK and Musculoskeletal Research Group, Institute of Cellular Medicine, Newcastle University.

Corresponding author: KL Hackett, katie.hackett@ncl.ac.uk

In this article the CRESTA team share reflections on their service development to set up a novel clinic to manage fatigue symptoms following an audit which identified such a need for all fatigue patients regardless of diagnosis. Here they describe their innovative clinic approach.

Abstract

Fatigue is a debilitating symptom affecting quality of life and ability to perform daily activities, and is experienced by up to 70% of patients with rheumatological diseases. Many patients do not feel their fatigue is appropriately managed by their medical teams, and no services up until this point enabled patients with chronic fatigue, irrespective of their long-term physical health condition, to access a multidisciplinary team (MDT). The CRESTA Fatigue Clinic was formed in response to this unmet need. It is a novel approach to treating on symptom-based, not disease-based, criteria. It has proved successful and we suggest it is the future of managing fatigue in chronic diseases.

Background

Fatigue, whether as a side effect of a chronic disease or as part of the constellation of symptoms leading to chronic fatigue syndrome (CFS), is increasingly prevalent within the UK. Chronic diseases are set to be the biggest cause of disability by 2020 (WHO 2014), with the frequently associated symptom of fatigue contributing significantly. Studies demonstrate that 25% of primary care consultations are attributable to fatigue, and it is the primary reason for consultation in 6.5% of cases (Cullen and Bury 2002). Rheumatological diseases are no exception, with fatigue being a large component of the patient experience of conditions such

as primary Sjögren's syndrome (pSS), Ehlers-Danlos syndrome (EDS), joint hypermobility syndrome (JHS) and systemic lupus erythematosus (SLE), as well as in the more prevalent conditions of rheumatoid arthritis (RA) and ankylosing spondylitis (AS) (Voermans et al 2010; Dupond 2011). Overall, studies suggest that up to 70% of rheumatic patients have fatigue, and of these, approximately 50% feel it is not appropriately managed by their physician (Dupond 2011). This is further supported by studies which suggest some patients perceive a lack of interest in fatigue by their rheumatologists (Hewlett et al 2005). Fatigue significantly impacts upon quality of life and ability to perform daily activities (Ward 1999; Hackett et al 2012b; Murphy et al 2013; Schmeding and Schneider 2013; Lendrem et al 2014) and occupational therapists are therefore ideally suited to support patients with fatigue management (Hackett et al 2012a; Kos et al 2012). Current guidance for the management of CFS fatigue recommends an individually tailored activity management programme which draws on principles of cognitive behavioural therapy and graded exercise therapy, and includes sleep management and vocational support as appropriate (NICE 2007). Rheumatologist and nurse specialists are aware that rheumatology patients experience fatigue; however, many clinicians rely on the patient to raise the issue. Furthermore, if fatigue is mentioned within a consultation, there can be uncertainty regarding both supportive interventions and who should deliver them (Repping-Wuts et al 2008; Repping-Wuts et al 2009). A recent multi-centred survey has demonstrated that 82% of inflammatory arthritis patients would accept support for pain and fatigue if such a service was available to them (Dures et al 2014). In this paper we describe a new multidisciplinary fatigue service which provides support to people with chronic fatigue

associated with a long-term condition.

The development of the CRESTA Fatigue Clinic

As in CFS, fatigue in rheumatological conditions has a negative impact on functional ability and quality of life (Bombardier and Buchwald 1996; Kiani and Petri 2010; Lendrem et al 2014). An audit carried out in the Newcastle UK CFS clinical service found that 40% of those referred were not eligible to access treatment due to the cause of their fatigue being attributable to a co-existing disease, which is an exclusion for multidisciplinary access (Newton et al 2010). While there are many successful CFS services across the NHS, there were no services aimed at those who suffer with fatigue outside of CFS. In addition, there is an increasingly recognised proportion of fatigued patients with dysautonomia (autonomic dysfunction) who could benefit from a specialist multidisciplinary team approach (Louthrenoo et al 1999; Kanjwal et al 2010; Newton et al 2012). A common form of dysautonomia seen is postural tachycardia syndrome (PoTS), which is defined by a 30 beats per minute rise in heart rate upon standing (Benarroch 2012).

Without the support that they need, many patients with severe fatigue experience a reduction in their quality of life (Kiani and Petri 2010; Lendrem et al 2014). These complications create a large burden to general NHS services, which may not be adequately resourced to support patients to manage their fatigue symptoms (Dures et al 2014). Consequently, the Newcastle Clinics for Research & Service in Themed Assessment (CRESTA) Fatigue Clinic was formed. It aimed to fill this gap in service provision and treat on a symptom-based, not diagnosis-based approach, rather like the UK chronic pain services.

The clinic is based on an established Dutch model (Vermoeidheid & Pijn Centrum) and is situated in the

Newcastle University Campus for Ageing and Vitality, in a modern and relaxed environment. At the foundation of the clinic in 2013, there was a medical clinician, occupational therapist and health psychologist. This has gradually increased to include a sleep therapist and physiotherapist, along with nursing staff.

A multidisciplinary approach to managing fatigue

The CRESTA Fatigue Clinic represents an innovative approach to managing fatigue in people with rheumatological and other chronic diseases. Our experience highlights that a large range of patients with differing diagnoses and needs are accessing this service. Of these, a large proportion of referrals are patients with rheumatological diseases (36.5%); 8.4% (17/200) of our patients have pSS, 19.5% (39/200) have EDS or JHS, and 8.4% (17/200) are other rheumatological conditions. Our medical clinician, in addition to investigating any changes needed to medication, also has a particular interest in management of dysautonomia. Assessment of the integrity of the autonomic nervous system is performed in all new patients attending the clinic. This assessment is performed using continuous beat-to-beat technology (CN Systems; Taskforce monitor) in order to examine autonomic function at rest and in response to the haemodynamic stress of orthostasis (standing).

Symptoms of autonomic dysfunction include postural dizziness and heart palpitations (Sandroni et al 1999). These are considered when planning therapy interventions. The physician assesses which members of the team each patient would benefit from seeing, according to their presenting needs. The plan for each patient is tailored and is refined at subsequent appointments (Figure 1). This approach enables patients to be treated on an individual basis tailored to the clinical input that they need. We think this is the most effective way to use our resources because of the heterogeneous

patient group accessing the clinic. Occupational therapy is important, as patients' fatigue symptoms impact on many of their day-to-day activities (Hackett et al 2012a; Murphy et al 2013; Schmeding and Schneider 2013). An assessment builds on the medical evaluation and includes identifying specific difficulties with activities of daily living, social and family support networks, mapping a typical day's activities and an assessment of sleep. One common problem is prioritising available energy on perceived 'essential' activities such as work or childcare, at the expense of social and leisure activities. Restricting social and leisure occupations can result in a disruption in occupational balance and can impact on quality of life (Backman 2004). Occupational therapy seeks to address this imbalance using appropriate strategies, such as goal setting and planning activities prospectively, to ensure physical and mental activities are interspersed with rest. A graded approach to increasing the patient's chosen activity or exercise is taken with a view to making steps towards their longer-term goals. The content of the individual therapy sessions is tailored to individual needs and may include education about fatigue, support to balance different types of day-to-day activities and rest, as well as support with sleep. Furthermore, patients of working age are offered elements of vocational rehabilitation as appropriate, such as suggesting reasonable adjustments in the workplace and liaising with the employer.

Many of our patients have a sedentary lifestyle, to avoid the extreme fatigue experienced by being active. As a result, they have become de-conditioned and weakened, especially in their core stability. Our physiotherapist offers interventions to improve core strength and flexibility and to build up physical activity. Postural dizziness is also addressed in physiotherapy and a graded approach

is taken to support patients with significant autonomic dysfunction to tolerate being upright for extended periods. As the clinic evolved, an exercise class was started, as it was observed that many of our patients needed similar physiotherapy input and the social aspect to classes also acts to motivate participants. This has been a successful intervention which enables more patients to have regular access to physiotherapy.

Our health psychologist offers individual cognitive behavioural therapy and works collaboratively with patients to understand the range of biopsychosocial factors that may be involved in the onset and maintenance of their fatigue and other physical symptoms, and to develop coping strategies accordingly. Equally important is collaborative working around acknowledging and managing the practical and emotional aspects of the biographical disruption (Bury 1982) that almost always accompanies the experience of chronic physical symptoms.

Patients who experience more daytime fatigue also perceive poorer sleep quality (McDonald et al 2014). The consequences associated with poor sleep can be substantial, resulting in increased fatigue. Patients with conditions such as PoTs, pSS and EDS/JHS all report sleep disturbances (Verbraecken 2001; Theander 2010; Bagai 2011). Our sleep therapist performs cognitive behavioural therapy for insomnia (also known as CBT-I), which aims to re-establish regularity in patients' sleeping patterns and improve sleep quality, which in turn may improve outcomes in other areas of treatment for their condition (ie, reduced fatigue severity (Thorndike et al 2013)).

Although all the therapists in the team have their own specific areas of expertise, they work closely together and interventions offered by each

member of the team do overlap. The interdisciplinary approach which has been adopted by the CRESTA Fatigue Clinic means that therapists are able to offer each other peer supervision. Furthermore, referrals between therapists occur if a certain therapist has the skills required for a particular patient's needs.

Many patients who come to the CRESTA Fatigue Clinic have had relatively poor experiences elsewhere due to the fact there has been nowhere, until now, for this patient group to easily access a multidisciplinary team for support with their fatigue symptoms. This dissatisfaction has been reported in the literature (Hewlett et al 2005). CRESTA Fatigue Clinic service users have expressed their satisfaction of the service the clinic provides, stating:

"I would like to thank you and your team for the wonderful care I received during my clinic visit. It was refreshing to meet a team so clearly focused on meeting patients' needs. I have never been anywhere else where the needs of patients with CFS and similar illnesses are met so well. I am very grateful for your kindness, great care and consideration."

"Thank you more than I can say for your support in understanding and validating my struggle with PoTs, CFS/ME (chronic fatigue syndrome/ myalgic encephalomyelitis) etc... I feel I have been given my life back. After struggling so long, beyond endurance, words can't describe the relief. It has actually brought a kind of 'shock', but the wonderful thing is that this is ok; there isn't a deadline – only a lifeline. When I made that epic journey to come to you and your team I tried hard not to invest 'too much' hope, but I couldn't help it; it was like my last little bit of hope. Oh and it was so worth it. To come into that lovely cheery environment, to not have

to explain my condition because your team and you 'get it' is so affirming."

Future developments

The clinic continues to develop as we learn from what we have seen. Patients travel from across the UK to access our clinic, indicating at the very least that there is a need for this kind of service that is not being met elsewhere in the country. To more objectively determine the success of the clinic, we have performed a rigorous service evaluation. A concept-mapping study design was used (paper currently under review) which showed the areas that patients thought were important, such as "taking my fatigue seriously" and "face-to-face contact", were being met successfully at the clinic. While this unique clinic is still in its infancy, it is clear to see it is successfully meeting patients' expectations.

We continue to strive to improve our service and we have input from a group of expert patient 'health champions', with a funded project (Altogether Better 2015), which ensures patients' views remain at the centre of what we do. We are also creating interdisciplinary CRESTA notes in a booklet to keep all of our interventions

in one area of patient notes to ensure continuity of care.

Future service developments are targeted on areas identified in the service evaluation. With fatigue becoming an ever-increasing health burden due to the ageing population (Enkvist et al 2012; Egerton 2013), we need to think about how to meet this demand nationally. In the North East, with the evolution of the CRESTA Fatigue Clinic, we have begun the journey to achieve this. A more immediate way of offering support to patients with fatigue related to a rheumatological or other long-term condition could be by improving access to appropriately trained therapists through improving referral pathways, staffing levels and access to appropriate training and supervision.

It has long been recognised that pain is a symptom that needs specialist and multidisciplinary management, irrespective of its cause. We believe it is now time to approach fatigue in the same manner. In the CRESTA Fatigue Clinic we have established a model for the trans-diagnostic multidisciplinary assessment and management of fatigue. We believe that this could be replicated across the country to provide the kind of help for fatigue that is currently

available to pain patients within NHS pain clinics.

Acknowledgments

A College of Occupational Therapists' Innovation Award funded the service evaluation. KH receives funding from Arthritis Research UK (grant number: 20169). Neither the College of Occupational Therapists nor Arthritis Research UK had any involvement in the design, conduct, data collection, data management, analysis, interpretation of the data or approval of the manuscript. We would also like to acknowledge the CRESTA Fatigue Clinic patients for their constructive feedback.

Conflict of interest: none declared

References

- Altogether Better (2015) *Altogether better: unlocking the power of communities to transform lives*. Available at: <http://www.altogetherbetter.org.uk/> (Accessed on 18/02/2015).
- Backman CL (2004) 'Occupational balance: exploring the relationships among daily occupations and their influence on well-being'. *Canadian journal of occupational therapy*, 71(4), 202-209.
- Bagai K, et al (2011) 'Sleep Disturbances and Diminished Quality of Life in Postural Tachycardia Syndrome'. *Journal of Clinical Sleep Medicine*, 7(2), 204-10.
- Benarroch EE (2012) 'Postural Tachycardia Syndrome: A Heterogeneous and Multifactorial Disorder'. *Mayo Clinic Proceedings*, 87(12), 1214-1225.
- Bombardier CH and Buchwald D (1996) 'Chronic Fatigue, Chronic Fatigue Syndrome, and Fibromyalgia: Disability and Health-Care Use'. *Medical Care*, 34(9), 924-930.
- Bury M (1982) 'Chronic illness as biographical disruption'. *Sociology of Health & Illness*, 4(2), 167-82.
- Cullen WK, Y. Bury, G. (2002) 'Prevalence of fatigue in general practice'. *Irish Journal of Medical Science*, 171, 10-12.
- Dupond JL (2011) 'Fatigue in patients with rheumatic diseases'. *Joint Bone Spine*, 78(2), 156-160.

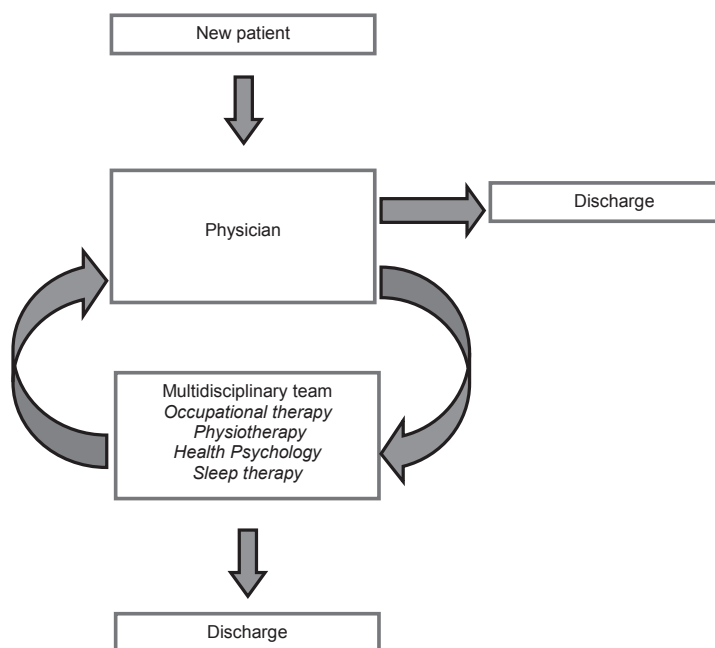


Figure 1: Flow diagram of patients attending CRESTA Fatigue Clinic

- Dures E, Almeida C, Caesley J, Peterson A, Ambler N, Morris M, Pollock J and Hewlett S (2014) 'Patient preferences for psychological support in inflammatory arthritis: a multicentre survey'. *Annals of the Rheumatic Diseases*.
- Egerton T (2013) 'Self-reported aging-related fatigue: a concept description and its relevance to physical therapist practice'. *Phys Ther*, 93(10), 1403-13.
- Enkvist A, Ekstrom H and Elmstahl S (2012) 'Life satisfaction (LS) and symptoms among the oldest-old: results from the longitudinal population study called Good Aging in Skane (GAS)'. *Archives of Gerontology and Geriatrics*, 54(1), 146-50.
- Hackett K, Newton J and Ng WF (2012a) 'Occupational therapy: a potentially valuable intervention for people with primary Sjogren's syndrome'. *British Journal of Occupational Therapy*, 75(5), 247-249.
- Hackett KL, Newton JL, Frith J, Elliott C, Lendrem D, Foggo H, Edgar S, Mitchell S and Ng W-F (2012b) 'Impaired functional status in primary Sjögren's syndrome'. *Arthritis Care & Research*, 64(11), 1760-1764.
- Hewlett S, Cockshott Z, Byron M, Kitchen K, Tipler S, Pope D and Hehir M (2005) 'Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored'. *Arthritis Care & Research*, 53(5), 697-702.
- Kanjwal KSB, Karabin B, Kanjwal Y and Grubb BP (2010) 'Comparative Clinical Profile of Postural Orthostatic Tachycardia Patients With and Without Joint Hypermobility Syndrome'. *Indian Pacing and Electrophysiology Journal* 10(4).
- Kiani A and Petri M (2010) 'Quality-of-Life Measurements Versus Disease Activity in Systemic Lupus Erythematosus'. *Current Rheumatology Reports*, 12(4), 250-258.
- Kos D, Nijs J, Meirte J, Willekens B, Nagels G and D'Hooghe MB (2012) 'The effectiveness of a self-management occupational therapy intervention on activity performance in persons with MS-related fatigue: a randomized clinical trial'. *Multiple Sclerosis Journal*, 18(5), S46-S47.
- Lendrem D, Mitchell S, McMeekin P, Bowman S, Price E, Pease CT, Emery P, Andrews J, Lanyon P, Hunter J, Gupta M, Bombardieri M, Sutcliffe N, Pitzalis C, McLaren J, Cooper A, Regan M, Giles I, Isenberg D, Vadivelu S, Coody D, Dasgupta B, McHugh N, Young-Min S, Moots R, Gendi N, Akil M, Griffiths B, Ng WF and Registry UKpSsS (2014) 'Health-related utility values of patients with primary Sjogren's syndrome and its predictors'. *Ann Rheum Dis*, 73(7), 1362-8.
- Louthrenoo W, Ruttanaumpawan P, Aramrattana A and Sukitawut W (1999) 'Cardiovascular autonomic nervous system dysfunction in patients with rheumatoid arthritis and systemic lupus erythematosus'. *QJM*, 92(2), 97-102.
- McDonald CK, Koshi S, Busner L, Kavi L, Newton JL (2014) 'Postural tachycardia syndrome is associated with significant symptoms and functional impairment predominantly affecting young women: a UK perspective'. *BMJ open*, 4(6), e004127.
- Murphy SL, Alexander NB, Levoska M and Smith DM (2013) 'Relationship between fatigue and subsequent physical activity among older adults with symptomatic osteoarthritis'. *Arthritis Care and Research*, 65(10), 1617-24.
- Newton JL, Frith J, Powell D, Hackett K, Wilton K, Bowman S, Price E, Pease C, Andrews J, Emery P, Hunter J, Gupta M, Vadivelu S, Giles I, Isenberg D, Lanyon P, Jones A, Regan M, Cooper A, Moots R, Sutcliffe N, Bombardieri M, Pitzalis C, McLaren J, Young-Min S, Dasgupta B, Griffiths B, Lendrem D, Mitchell S and Ng W-F (2012) 'Autonomic symptoms are common and are associated with overall symptom burden and disease activity in primary Sjögren's syndrome'. *Annals of the Rheumatic Diseases*, 71(12), 1973-1979.
- Newton JL, Mabillard H, Scott A, Hoad A and Spickett G (2010) 'The Newcastle NHS Chronic Fatigue Syndrome Service: not all fatigue is the same'. *The journal of the Royal College of Physicians of Edinburgh*, 40(4), 304-7.
- NICE (2007) 'Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of CFS/ME in adults and children'. *NICE clinical guideline* 53.
- Repping-Wuts H, Hewlett S, van Riel P and van Achterberg T (2009) 'Fatigue in patients with rheumatoid arthritis: British and Dutch nurses' knowledge, attitudes and management'. *Journal of Advanced Nursing*, 65(4), 901-911.
- Repping-Wuts H, van Riel P and van Achterberg T (2008) 'Rheumatologists' knowledge, attitude and current management of fatigue in patients with rheumatoid arthritis (RA)'. *Clinical Rheumatology*, 27(12), 1549-1555.
- Sandroni P, Opfer-Gehrking TL, McPhee BR and Low PA (1999) 'Postural Tachycardia Syndrome: Clinical Features and Follow-up Study'. *Mayo Clinic Proceedings*, 74(11), 1106-1110.
- Schmeding A and Schneider M (2013) 'Fatigue, health-related quality of life and other patient-reported outcomes in systemic lupus erythematosus'. *Best Practice & Research: Clinical Rheumatology*, 27(3), 363-75.
- Theander L, et al (2010) 'Sleepiness or fatigue? Can we detect treatable causes of tiredness in primary Sjögren's syndrome?' *Rheumatology*, 49(6), 1177-1183.
- Thorndike FP, Ritterband, L. M., Gonder-Frederick LA, Lord HR, Ingersoll KS, & Morin CM (2013) 'A randomized controlled trial of an Internet intervention for adults with insomnia: effects on comorbid psychological and fatigue symptoms'. *Journal of clinical psychology*, 69(10), 1078-1093.
- Verbraecken J et al (2001) 'Evaluation for sleep apnea in patients with Ehlers-Danlos syndrome and Marfan: a questionnaire study'. *Clinical Genetics*, 60(5), 360-365.
- Vermoeidheid & Pijn Centrum*. Available at: <https://www.vermoeidheidcentrum.nl/over-ons> (Accessed on 31/03/2015).
- Voermans NC, et al (2010) 'Fatigue Is a Frequent and Clinically Relevant Problem in Ehlers-Danlos Syndrome'. *Seminars in Arthritis and Rheumatism*, 40(3), 267-274.
- Ward MM (1999) 'Health-related quality of life in ankylosing spondylitis: A survey of 175 patients'. *Arthritis Care & Research*, 12(4), 247-255.
- WHO (2014) *Global status report on noncommunicable diseases*. Geneva: World Health Organisation.