

<p><b>Institution: University of Cumbria</b></p>
<p><b>Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy</b></p>
<p><b>Title of case study:</b> Improving the uptake of Occupational Therapy as an evidenced-based intervention to improve management of Chronic Fatigue Syndrome.</p>
<p><b>1. Summary of the impact</b></p> <p>The work of Professor Diane Cox has been instrumental in enhancing services and improving outcomes for patients with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME), and other fatigue related conditions. Primarily, this has been through changing the interventions used by Occupational Therapists and other Allied Health Professionals in healthcare practice to manage such conditions. The research has influenced amendments to professional standards, guidelines and training for use of activity and lifestyle management approaches to treating CFS and related conditions, and has had further impact through influencing the set-up of specific CFS services using these techniques. The research has demonstrated that Occupational Therapy can improve engagement and participation in occupations through activity, and led to its widespread uptake into practice throughout the UK. The research has underpinned the National Institute for Health and Clinical Excellence (NICE) guidelines for CFS/ME and directly influenced the form and implementation of NHS and private service provision for these conditions in the UK.</p>
<p><b>2. Underpinning research</b></p> <p>The research was begun by Cox whilst working in the NHS as an Occupational Therapist through the set up and appraisal of interventions in an Occupational Therapy led CFS service (1988-1998). This was then furthered at a previous HEI (1998-2000) and at the University of Cumbria since Professor Cox's appointment in September 2000 as a Senior Lecturer at St Martin's College, one of the legacy institutions which became part of the University on formation in 2007. Cox was promoted to Reader in February 2005, and Professor of Occupational Therapy in May 2011.</p> <p>Early work identified the role of Occupational Therapy in managing fatigue and identified the four levels of occupational disruption, which have subsequently influenced treatment and organisation of specialist CFS / ME and other fatigue services. Subsequent research at Cumbria has identified the effectiveness of Occupational Therapy interventions and identified treatment approaches and factors which affect patient outcomes.</p> <p>Whilst led by Professor Cox, the work has been in collaboration with a number of other Higher Education Institutions, the Department of Health and NHS Trusts in the UK. A number of studies have supported the work from a process, pathway and intervention perspective, with the overarching theme of encouraging engagement and participation in occupations through activity.</p> <p>Key research projects for Professor Cox include:</p> <ul style="list-style-type: none"> <li>• PACE Trial. <u>P</u>acing, <u>A</u>ctivity and <u>C</u>ognitive Behaviour Therapy: a randomised <u>e</u>valuation. Funded 2004-2011. Cox's contribution to PACE included writing therapist and participant Adaptive Pacing Therapy (APT) manuals, and training and supervising the Occupational Therapists undertaking the APT treatment arm of the trial, in addition to contribution to the research design and resultant publications.</li> <li>• The use of Telecare/ Telerehabilitation in the management of CFS/ ME, North Cumbria CFS Service. 2008-2010.</li> <li>• Exploration of the experience of a Mindfulness programme for adults with CFS/ ME. North Cumbria CFS Service. 2009-2010</li> <li>• Recovery Focussed Communication Study. Collaboration with Dorset CFS/ ME Service, University of Southampton, Bournemouth University, University of Cumbria. 2010-2012.</li> <li>• The relationship of Occupational Therapy to time, tempo and temporality in CFS/ ME.</li> <li>• Systematic literature review to determine the evidence on clinical interventions for severe Chronic Fatigue Syndrome/ME Collaboration with Dorset CFS/ ME Service, University of Southampton, University of Cumbria. July 2012-July 2013</li> </ul> <p>The main research insights include:</p>

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- The defining of the wide range of occupational disruption in CFS/ ME into the four levels of mild, moderate, severe and very severe. The levels of ability defined through the audits, surveys and intervention studies (adopted by NICE Guidance 2007 and re-adopted in 2011). (Whilst this work primarily took place before joining Cumbria (Cox and Findley, 1998), the exploration and testing of this structure in practice is the basis for subsequent work by Cox, which has enhanced treatment practices provided by practitioners).
- The level of severity of CFS/ ME does not preclude improvement (further research currently in progress; collaboration with the University of Southampton).
- Active treatment that includes activity and cognitive grading has a better outcome than pacing alone (White et al 2011).
- Time & Occupational domains influence perception of activity management (Pemberton & Cox 2011, 2013).
- Tele-rehabilitation is feasible and acceptable to people with CFS/ME (Steel, Garry, Cox 2011).
- Video-conferencing has benefit and value as a face-to-face intervention mode of delivery for those in rural communities with issues of access to treatment due to geography and transport.

### 3. References to the research

- PD White, KA Goldsmith, AL Johnson, L Potts, R Walwyn, JC DeCesare, HL Baber, M Burgess, LV Clark, **DL Cox**, J Bavinton, BJ Angus, G Murphy, M Murphy, H O'Dowd, D Wilks, P McCrone, T Chalder, M Sharpe, on behalf of the PACE trial management group (2011). Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. Online, February 18, 2011, *The Lancet* 377: 823-836.
- Steel K, **Cox DL**, Garry H (2011) Videoconferencing face-to-face therapeutic interventions for the treatment of long term conditions *Journal of Telemedicine and Telecare* 17;3:109-117; first published on 21 February 2011.
- **Cox DL**, Araoz G (2009) Experience of therapist supervision within a multi-centre randomised controlled trial. *Learning in Health & Social Care* 8; 4: 301-314.
- Pemberton S, Cox DL (2013) Perspectives of Time and Occupation: Experiences of People with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis *Journal of Occupational Science* first view on-line 4th June 2013.

### Grants;

- PACE Trial, multi-centred randomised controlled trial. Medical Research Council (MRC) £3.5million grant awarded to Profs PD White (QML & Barts), M Sharpe (Edin), T Chalder (KCL); co-investigator 2004-2011. UKCRN ID 4502. 2004-2011.
- The use of Telerehabilitation in the management of CFS/ ME, Grant from Northern CFS/ME Clinical Network £20,000 to support a Research Assistant. Awarded to Heather Garry (Cumbria PCT) and Diane Cox 2007-2009.
- The Management of Fatigue in patients with Advanced Cancer: a pilot randomised controlled trial of a customised rehabilitation intervention. £45,000 from Oxfordshire Health Services Research Committee (OHSRC) Special Cancer Research Grant. Awarded to Mary Barker (nee Black), Oxford Hospitals NHS Trust, 2007-2009.

### 4. Details of the impact

Professor Cox's research has directly influenced the take-up of Occupational Therapy as a key intervention in the treatment of CFS/ME. It has directly underpinned advances in the understanding of how fatigue conditions are experienced in terms of occupational disruption, and has trialled and disseminated Occupational Therapy interventions which provide an effective treatment for this and related conditions. Primarily, the research has provided evidence for interventions to improve outcomes for mild and moderate presentations of CFS, and has pioneered the use of video conferencing to improve access to patients with more severe presentations. It has also led to the improvement of Occupational Therapy practice through direct engagement with practitioners and

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services and through training provision of practitioner training, based on the research insights.

Identification of the levels of occupational disruption was taken up in the 2007 NICE guidelines, which have subsequently been implemented into specialist services. Subsequent work has concentrated on the effective management through Occupational Therapy interventions, which was taken into account during the 2011 guideline review, which specifically noted the PACE trial as supporting the NICE guideline recommendations. The work therefore directly underpins the practice of managing CFS in the UK. The PACE trial itself also has direct implications for practice, as it indicated that less active treatments such as APT did not have the same impact on improvement as Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET). Activity Management and graded activity is a key component of both CBT and GET. The trial showed that when pacing is used in isolation of other graded programmes it is less effective. These findings, which are further influencing practice in management of CFS, is directly related to Professor Cox's research, as the research lead on the APT elements of the trial.

Influence on practice and service delivery has been effected both through direct engagement with providers of treatment and interventions (both public and professional) and through dissemination to stakeholders through practitioner orientated publications. Research reports and reprints by professional bodies include:

1. Pemberton, S. & Cox, D. (2011) What happened to time? The relationship of occupational therapy to time. *British Journal of Occupational Therapy*, 74, 78-85  
**Reprinted in Full In;** *Perspectives for Occupation-Based Practice*, 3<sup>rd</sup> edition. (2013) Bethesda: American Association of Occupational Therapy (AOTA).
2. Wright F, Cox DL (2012) *The Use & Meaning of Activity Management: A short summary report* University of Cumbria & North Bristol NHS Trust.
3. Cox DL (2012) Chapter 19; Chronic Fatigue Syndrome, In, Matthews, G., Desmond, P.A., Neubauer, C., & Hancock, P.A. (Eds.), *The Handbook of Operator Fatigue*. Farnham, Surrey, UK: Ashgate Publishing. ISBN: 978-0-7546-7537-2.
4. Steel K, H (2009) *Using desktop videoconferencing for delivery of CFS/ME interventions at home in the North Cumbria area: a pilot trial*, NHS Cumbria.

The exploratory research for NHS Cumbria has been used to support the delivery of services via video-conferencing, and as a basis to seek further funding for this method of intervention and for further research to support this. Professor Cox also receives frequent requests from practitioners for copies of these commissioned reports and articles in practitioner orientated journals to aid in setting up the videoconferencing approach in practice. Such interest extends beyond Occupational Therapy interventions for CFS, and is valued by NHS Trust policy makers exploring telerehabilitation and telecare more widely. The *British Journal of Occupational Therapy* (BJOT) is a particularly important tool for reaching practitioners, as the only monthly peer-reviewed occupational therapy journal in the world, and subscribed to in over 40 countries worldwide as well as being sent monthly to all British Association of Occupational Therapy members.

Professor Cox has directly contributed to the creation and development of specialist CFS/ME services (such as Dorset, Chester, North Cumbria). An example of development of services is involvement with the Dorset CFS service, including review of a recovery focussed programme. For North Cumbria CFS service this has involved piloting the use of telecare, which particularly benefits service delivery in a region characterised by rural and remote geography. Other work for North Cumbria has included evaluating the effectiveness of a mindfulness programme for adults with CFS / ME. Impact through supporting the establishment of CFS services has included sitting on the Department of Health CFS/ME Service Investment Steering Group that enabled the pump priming of new services in England and through informing the content of rehabilitation programmes for the service including energy and activity management. The programme has been a catalyst to inform professionals, patients and carers nationally. Professor Cox also provides professional supervision to a number of individuals, directly influencing the services provided. These individuals practice across the country, at North Cumbria CFS/ME Service (NHS Cumbria); South Coast

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Fatigue Ltd, Hampshire; ME North East, Newcastle, and Lancashire CFS/ ME Service.

The research insights have also been disseminated directly to practitioners through a range of professional body conferences and other engagement events. This includes at the College of Occupational Therapists Annual Conference on a number of occasions, such as specific discussion of experience of time and of telecare interventions, and at other events, such as the International Congress on Telehealth and Telecare and the British Association of CFS/ ME (BACME) conference.

Professor Cox has also delivered a range of continuing professional development events within the period, including:

- Chronic Fatigue Research, Cumbria & Lancashire Comprehensive Local Research Networks (CLRN) Musculoskeletal group, Lancaster University, February 2009.
- Chronic Fatigue Syndrome Northern Clinical Coordinating Centre Conference, CFS/ ME Therapy: activity management for people with CFS/ ME, Crosthwaite Conference Centre, Keswick, Cumbria, October 2009.
- Update on Chronic Fatigue Syndrome Therapy Research, Queens Hospital, Romford, Essex, November 2009.
- *Keeping it tight: Quality control for intervention adherence and therapeutic alliance in a multi-centred RCT*, Oxford Brookes University, Oxford, November 2011.
- Activity Management in CFS/ ME for the CFS/ME Collaborative and Network Training. Manchester, October 2008.
- AHP Training in the Management of Chronic Fatigue Syndrome, St. Cyril's Rehabilitation Unit, Chester, April 2010.

These examples include training provided to a mixed audience of Health Professionals: Occupational Therapists, Physiotherapists, Nurses, Psychologists and GPs. The research was used as a foundation for the training and where appropriate actually demonstrated aspects of Activity Management within GET and CBT. The training therefore had a direct impact on clinical practice and the shaping of evidence based services for CFS/ ME in the UK, and methodological issues of research in practice.

### 5. Sources to corroborate the impact

- Annual report for Northern CFS/ME network citing impact of the telecare research. [http://www.bacme.info/document\\_uploads/BACME\\_docs/NorthernCFSMENetworkAnnualReport201011.pdf](http://www.bacme.info/document_uploads/BACME_docs/NorthernCFSMENetworkAnnualReport201011.pdf)
- NICE guideline review, 2011, citing PACE trial results. <http://www.nice.org.uk/nicemedia/live/11824/53532/53532.pdf>
- Email requests from practitioners and NHS Trust policymakers for copies of research outputs to inform service delivery, available on request.

Contacts to corroborate impact on practice in specialist CFS services:

- Specialist Occupational Therapist and Director, South Coast Fatigue.
- Therapy Director and Specialist Occupational Therapist, Yorkshire Fatigue Clinic.
- Occupational Therapist, North Cumbria CFS/ME Service, Cumbria Partnership NHS Foundation Trust; (including impact on technology as a means of delivering services in a rural location).

Statement to corroborate impact on practice in specialist CFS services and through professional supervision:

- Research Fellow, Primary Medical Care, University of Southampton.