

Jornada para pacientes y familiares. Actualidad SFC/EM y SQM

FECHA: 25 de abril 2015
HORARIO: 9:30 a 14:00 h.
LUGAR: Hospital Clínico San Carlos. Avda Durán Sacristán.
Entrada por auditorio, frente a puerta P, oncología

ORGANIZA: SFC - SQM Madrid. Asociación de Afectados por Síndrome de Fatiga Crónica (SFC) y por Síndrome de Sensibilidad Química Múltiple (SQM) de la Comunidad de Madrid
www.sfcsgm.com 91 169 79 05 (de 11 a 14 h.)

COLABORA:    

PATROCINA:      

INVESTIGACIÓN EN FISIOTERAPIA

en el **Síndrome de Fatiga Crónica /
Encefalomiелitis Miálgica**

Presente y futuro...



ESCUELA UNIVERSITARIA DE FISIOTERAPIA
DE LA ONCE
UNIVERSIDAD AUTÓNOMA DE MADRID



Definición

El **Síndrome de Fatiga Crónica** (SFC) / **Encefalomiелitis Miálgica** (EM) es una enfermedad sistémica, seria, compleja y crónica que frecuentemente limita dramáticamente las actividades de los pacientes afectados.



IOM (Institute of Medicine). 2015. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. Washington, DC: The National Academies Press.

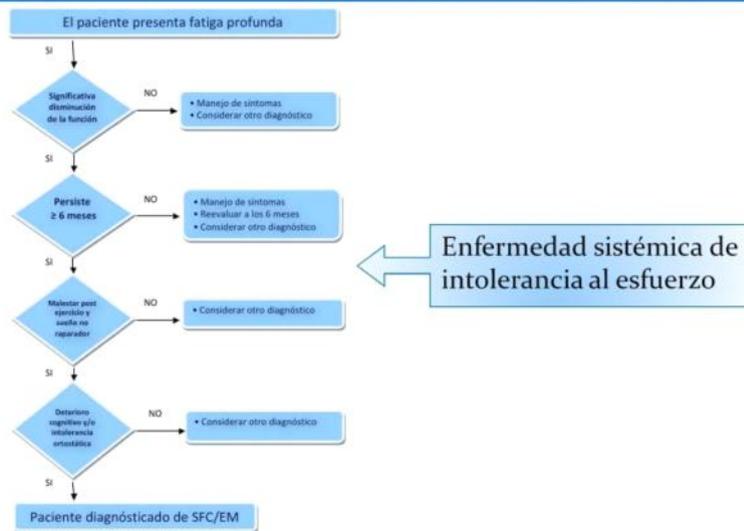
Prevalencia

- ✓ Hombre / Mujer 1:4
- ✓ 30 y 50 años.
- ✓ 0,075 y 2,54% de la población.
- ✓ España 40.000 personas afectadas.



Avellaneda A, Pérez A, Izquierdo M, Rivera J, Arruti M, Barbado FJ, et al. Documento de Consenso Español SFC- ISCI. AWW. Madrid, 2008.

Diagnóstico



IOM (Institute of Medicine). 2015. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. Washington, DC: The National Academies Press.

FISIOTERAPIA

¿Qué métodos y técnicas son **eficaces**?



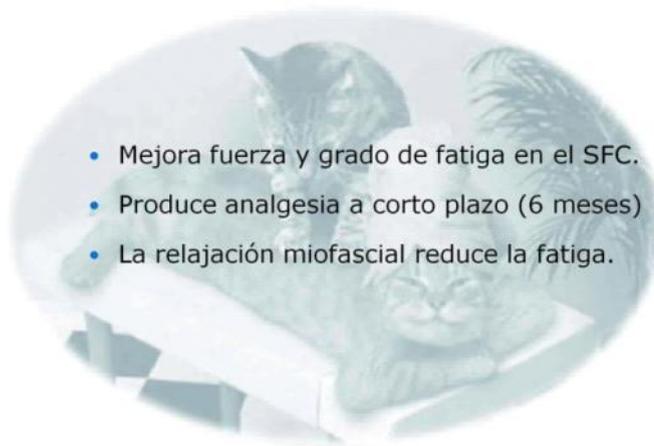
Fisioterapia Manual

Acupuntura

Electroterapia

Entrenamiento Gradual al Esfuerzo (GET)

Fisioterapia Manual



- Mejora fuerza y grado de fatiga en el SFC.
- Produce analgesia a corto plazo (6 meses)
- La relajación miofascial reduce la fatiga.

Yuan SL, Matsutani LA, Marques AP. Effectiveness of different styles of massage therapy in fibromyalgia: A systematic review and meta-analysis. *Man Ther*. 2015 Apr;20(2):257-264. doi: 10.1016/j.math.2014.09.003. Epub 2014 Oct 5.

Fisioterapia Manual

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January 2015 Volume 19, Issue 1, Pages 102-112

Next Article >

Effectiveness of myofascial release: Systematic review of randomized controlled trials

M.S. Alimsha, MPT, ADMFT, PhD , Noora R. Al-Mudahka, PT, MBA, J.A. Al-Madzhar, PT

Department of Physiotherapy, Hamad Medical Corporation, Doha, Qatar

Received: December 5, 2013; Received in revised form: June 4, 2014; Accepted: June 6, 2014; Published Online: June 12, 2014

Altmetric 12

DOI: <http://dx.doi.org/10.1016/j.libmt.2014.06.001>

Article Info

Abstract **Full Text** Images References

Fisioterapia Manual

< Previous Article

January 2015 Volume 19, Issue 1, Pages 102–112

Next Article >

Effectiveness of myofascial release: Systematic review of randomized controlled trials

Conclusions

The literature regarding the effectiveness of MFR was mixed in both quality and results. Although the quality of the RCT studies varied greatly, the result of the studies was encouraging, particularly with the recently published studies. MFR is emerging as a strategy with a solid evidence base and tremendous potential. The studies in this review may help as a respectable base for the future trials.

Altmetric 12

DOI: <http://dx.doi.org/10.1016/j.jbmt.2014.06.001>

Article Info

Abstract Full Text Images References

Acupuntura

Parece eficaz para reducir la fatiga aunque son necesarios más estudios y de mayor **calidad metodológica**.



Wang JJ, Song YJ, Wu ZC, Chu XO, Wang XH, Wang XJ, Wei LN, Wang QM. A meta analysis on randomized controlled trials of acupuncture treatment of chronic fatigue syndrome. Zhen Ci Yan Jiu. 2009 Dec;34(6):421-8.

Electroterapia

- Técnicas para el dolor crónico.
- Estimulación magnética transcraneal.
- T.E.N.S.



Nijs J, Meeus M, Van Oosterwijck J, Roussel N, De Koning M, Ickmans K, Matic M. Treatment of central sensitization in patients with 'unexplained' chronic pain: what options do we have?. *Expert Opin Pharmacother.* 2011 May;12(7):1087-98.

Ejercicio Físico Terapéutico

- **Es eficaz en el SFC/EM**
- **Necesario especificar el tipo de ejercicio e intensidad.**



Ejercicio Físico Terapéutico



El Entrenamiento Gradual al Esfuerzo es eficaz
(*Graded Exercise Therapy, GET*)

Larun L., Brurberg KG, Odgaard-Jensen J, Price JR. Exercise therapy for chronic fatigue syndrome. Cochrane Database of systematic reviews 2015, Issue 2. Art. No.:CD003200. DOI: 10.1002/14651858.CD003200.pub3.

Equipo de Investigación

- D. Fernando Montoya.
- D. José Casas Rivero.
- D. Antonio Goicolea de Oro.
- D. Luis Rodríguez Fuentes.
- D^a. Raquel Meizoso.
- D. Román Hermida.
- D. Joaquín Recas.
- D. José Manuel Bote Rosado.
- D. Francisco Rincón.
- D. Juan José Ramos Álvarez.
- D. Juan Carlos Segovia Martínez.
- D. Francisco Javier López-Silvarrey Varela.
- D^a. Susana García Juez.
- D^a. Irene Rodríguez Andonaegui.



Universidad Complutense
de Madrid
Facultad de Informática



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Ejercicio Físico Terapéutico

Investigación del Entrenamiento Gradual al Esfuerzo
con el objetivo de evitar el malestar postejercicio.



Terapia Cognitivo Conductual



Knoop H, Prins JB, Moss-Morris R, Bleijenberg G. The central role of cognitive processes in the perpetuation of chronic fatigue syndrome. J Psychosom Res. 2010 May; 68 (5):489-94.

Adaptative Pacing Therapy (APT)

Fatigue: Biomedicine, Health & Behavior, 2013
Vol. 1, Nos. 1–2, 27–42, <http://dx.doi.org/10.1080/21641846.2012.733602>



Energy conservation/envelope theory interventions

Leonard A. Jason*, Molly Brown, Abigail Brown, Meredyth Evans, Samantha Flores, Elisa Grant-Holler and Madison Sunnquist

Center for Community Research, DePaul University, Chicago, IL, USA

(Received 5 May 2012; final version received 8 August 2012)

Objectives: Treatment approaches for patients with chronic fatigue syndrome (CFS), Myalgic Encephalomyelitis (ME) and Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS) have been controversial. This paper provides the theoretical and conceptual background for the Energy Envelope Theory to assist patients and reviews evidence of its treatment efficacy. **Methods:** Over a 15-year period, efforts were directed to develop a non-pharmacologic intervention that endeavored to help patients to self-monitor and self-regulate energy expenditures

3 June 2013

Adaptative Pacing Therapy (APT)

Fatigue: Biomedicine, Health & Behavior, 2013
Vol. 1,



Energy
Leonard
Elisa C

Conclusion

Go to:

The series of studies summarized in this article provide support for the Energy Envelope Theory as an approach to the rehabilitation management of ME/CFS. This theory would recommend that health care professionals who treat patients with ME/CFS incorporate strategies that help patients self-monitor and self-regulate energy expenditures. Learning to pace activities and stay within the energy envelope appears to have favorable outcomes for patients with ME/CFS. Non-pharmacologic rehabilitative interventions are used for people with cancer and heart disease, but they are only one part of the treatment plan, and, when used by themselves, they are not curative. Similarly, helping patients with ME/CFS remain within their energy envelopes is only one part of a rehabilitation plan.

The Energy Envelope approach to ME/CFS symptom management and rehabilitation has important implications for health care practitioners who see individuals with ME/CFS. Although this approach is not curative, it may provide this patient population with strategies to aid in symptom management, which can significantly improve the quality of life for these individuals. There certainly is a need to include biological measures within future clinical trials with these types of approaches so that we can learn about who may profit most from these non-pharmacologic rehabilitation approaches, using outcomes beyond self-report measures. [34,36]

endeavored to help patients to self-monitor and self-regulate energy expenditures

3 June 2013

Author Manuscript

Adaptative Pacing Therapy (APT)

Disability & Rehabilitation, 2012; 34(13): 1140-1147
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ISSN 0963-8288 print/ISSN 1464-5165 online
DOI: 10.3109/09638288.2011.635746

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PERSPECTIVES IN REHABILITATION

Pacing as a strategy to improve energy management in myalgic encephalomyelitis/chronic fatigue syndrome: a consensus document

Ellen M. Goudsmit¹, Jo Nijs^{2,3,4}, Leonard A. Jason⁵ & Karen E. Wallman⁶

¹School of Psychology, University of East London, Stratford, London, E15 4LZ, UK, ²Department of Human Physiology, Faculty of Physical Education & Physiotherapy, Vrije Universiteit Brussel, Belgium, ³Division of Musculoskeletal Physiotherapy, Department of Health Care, Artesis University College Antwerp, Belgium, ⁴Department of Rehabilitation and Physiotherapy, University Hospital Brussels, Belgium, ⁵Center for Community Research, DePaul University, Chicago, IL USA, and ⁶School of Sport Science, Exercise and Health, The University of Western Australia

Purpose: Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a debilitating condition characterized by a number of symptoms which typically worsen following minimal exertion. Various strategies to manage the limited

Implications for Rehabilitation

- Pacing is a strategy which helps patients with ME/CFS limit exertion-related increases in symptomatology.

Hospital Ramon y Cajal on 04/21/15

Adaptative Pacing Therapy (APT)

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ISSN 0963-8288 print/ISSN 1464-5165 online
DOI: 10.3109/09638288.2011.635746

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to stabilize the condition and avoid post-exertional malaise. **Conclusion:** Pacing offers practitioners an additional therapeutic option which is acceptable to the majority of patients and can reduce the severity of the exertion-related symptoms of ME/CFS.

Implications for Rehabilitation

- Pacing is a strategy which helps patients with ME/CFS limit exertion-related increases in symptomatology.
- Pacing is appropriate for those who operating near or at their maximum level of functioning, and for individuals with neurological and immunological abnormalities.
- Pacing may be offered as part of an individualized, multi-component management programme.

minimal exertion. Various strategies to manage the limited

limit exertion-related increases in symptomatology.

Hospital Ramon y Cajal on 04/21/15

Adaptative Pacing Therapy (APT)

Journal List • Elsevier Sponsored Documents • PMC4066570



J Psychosom Res. 2014 Jul; 77(1): 20–25.
doi: [10.1016/j.jpsyres.2014.04.002](https://doi.org/10.1016/j.jpsyres.2014.04.002)

PMCID: PMC4066570

Adverse events and deterioration reported by participants in the PACE trial of therapies for chronic fatigue syndrome

[Dominic Dougall](#)^a, [Anthony Johnson](#)^b, [Kerriberay Goldsmith](#)^c, [Michael Sharpe](#)^d, [Brian Angus](#)^e, [Trude Chalder](#)^f and [Peter White](#)^g*

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Adaptative Pacing Therapy (APT)

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Conclusions

The numbers of adverse events did not differ significantly between trial treatments, but physical deterioration occurred most often after APT. The reporting of non-serious adverse events may reflect the nature of the illness rather than the effect of treatments. Differences between centres suggest that both standardisation of ascertainment methods and training are important when collecting adverse event data.

Adverse events and deterioration reported by participants in the PACE trial of therapies for chronic fatigue syndrome

[Dominic Dougall](#)^a, [Anthony Johnson](#)^b, [Kerriberay Goldsmith](#)^c, [Michael Sharpe](#)^d, [Brian Angus](#)^e, [Trude Chalder](#)^f and [Peter White](#)^g*

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Comparación de tratamientos

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Lancet. 2011 Mar 5; 377(9768): 823-835.
doi: [10.1016/S0140-6736\(11\)60086-2](https://doi.org/10.1016/S0140-6736(11)60086-2)

PMCID: PMC306633

Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial

PD White,^{a,*} KA Goldsmith,^b AL Johnson,^{c,d} L Potts,^b R Wakeyn,^b JC DeCesaire,^e HL Baber,^f M Burgess,^g LV Clark,^h DL Cox,^f J Bavinton,^g BJ Angus,^g G Murphy,^h M Murphy,^h H O'Dowd,ⁱ D Wilks,^h P McCrone,ⁱ T Chalder,^{h,*} M Sharpe,^{h,*} and on behalf of the PACE trial management group[†]

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Comparación de tratamientos

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Interpretation

CBT and GET can safely be added to SMC to moderately improve outcomes for chronic fatigue syndrome, but APT is not an effective addition.

Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial

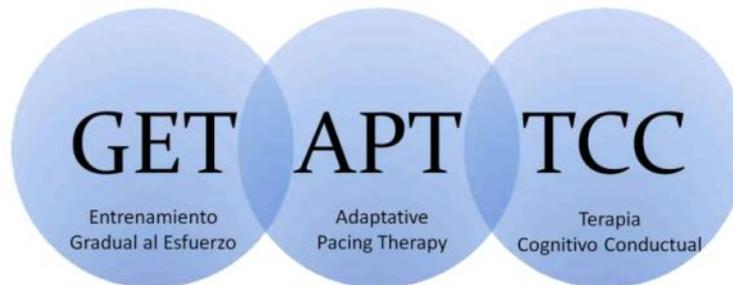
PD White,^{a,*} KA Goldsmith,^b AL Johnson,^{c,d} L Potts,^b R Wakeyn,^b JC DeCesaire,^e HL Baber,^f M Burgess,^g LV Clark,^h DL Cox,^f J Bavinton,^g BJ Angus,^g G Murphy,^h M Murphy,^h H O'Dowd,ⁱ D Wilks,^h P McCrone,ⁱ T Chalder,^{h,*} M Sharpe,^{h,*} and on behalf of the PACE trial management group[†]

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Comparación de tratamientos



Conclusiones

Líneas futuras de **investigación en Fisioterapia** en SFC/EM:

- Profundizar en cuál es el tipo, la intensidad y la duración de los ejercicios a emplear en el entrenamiento gradual al esfuerzo para producir los efectos más beneficiosos y minimizar el malestar post-ejercicio.
- Estudiar el efecto de la relajación miofascial con el objetivo de recuperar la presión diastólica y el ritmo cardíaco tras el ejercicio para comprobar si es capaz de reducir el malestar postejercicio en el SFC/EM.
- Investigar la eficacia del tratamiento multimodal, basado en el adaptative pacing therapy, la terapia cognitivo conductual, el entrenamiento gradual al esfuerzo y otras técnicas de Fisioterapia.



¡Muchas gracias por su atención!

Susana García Juez
Irene Rodríguez Andonaegui