



**CARDIFF AND VALE
UNIVERSITY HEALTH BOARD**

ME/CFS AND FIBROMYALGIA

ACTION PLAN 2015 – 2018

(January 2016)

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BACKGROUND

The Welsh Government reconvened the ME/CFS and Fibromyalgia (FM) Task and Finish Group in 2013. The recommendations were endorsed by the Minister for Health in 2014. Each Health Board was tasked to implement the recommendations through local delivery plans.

ME/CFS and Fibromyalgia are complex conditions. Challenges exist in accessing appropriate services and support. The Task and Finish Group identified eleven recommendations. These focused on integrated working, equity of care, development of local pathways for ME/CFS and Fibromyalgia for adults and children and raising awareness for the need for a timely diagnosis.

PREVALENCE

The true prevalence of ME/CFS and Fibromyalgia in the UK are unknown. Public Health Wales suggested using the mid-range prevalence rate of 0.3% for ME/CFS. Estimates for prevalence of Fibromyalgia report this condition affects 2% - 5% of the population with a female:male incidence ratio of 2:1.

The Office for National Statistics and 2011 Census information indicates Cardiff and The Vale population as 472,400 (Cardiff – 346,100 and the Vale 126,300). Cardiff has a considerably higher population density than any other authority area in Wales with 2,465 people per square kilometre.

CARDIFF AND VALE	
ME/CFS	0.3% population would be 1,417
Fibromyalgia	2.0% population would be 9,448

CURRENT SERVICE PROVISION

ME/CFS

ME/CFS involves a complex range of symptoms, including chronic and disabling fatigue, post exertional malaise, cognitive difficulties, sleep disturbance, recurrent infections and chronic pain. The pattern and intensity of symptoms vary between people and during the course of each individual's illness. It is estimated that 25% of people with ME/CFS have severe symptoms. It is acknowledged some patients experience symptoms that make it difficult to access outpatient care. ME/CFS is a chronic condition that dramatically limits the activities of daily life. The importance of an accurate diagnosis using a Diagnostic Algorithm in order to tailor care is paramount. The dysregulation of physiological symptoms

(Autonomic Nervous System, Immune Function and Neuroendocrine) need to be considered.

Currently patients are diagnosed within primary and secondary care. The diagnosis is made by first excluding other conditions. Referrals to secondary care are dependent on the presenting symptomatology and severity of symptoms. There is no identified pathway for ME/CFS within Cardiff and Vale at this time. An individual may be referred to Rheumatology, Physiotherapy, Neurology, Endocrinology, Rehabilitation Medicine, Infectious diseases, and Pain Services. If there is a primary pain problem they may also be seen within the Velindre Chronic pain Management Service. This service provides assessment and a self-management group and 1:1 work. The multidisciplinary team consists of an Administrator, Medical Consultant, clinical Psychologist and Senior Physiotherapist.

FIBROMYALGIA

Fibromyalgia is a chronic pain disorder characterised by widespread pain and muscle tenderness increased sensory awareness fatigue and non-restorative sleep disturbance, mood problems and cognitive disturbance. There is higher incidence of other functional problems including Irritable Bowel Syndrome, Temporomandibular Joint Disorder, Head Pain and Interstitial Cystitis. There is a complex interaction between physical, psychological and social factors that impact on functioning and quality of life.

Patients are diagnosed with Fibromyalgia in primary and secondary care. It is a clinical diagnosis made using an established diagnostic criteria. Patients may be sent to Rheumatology Specialists, Physiotherapy and Pain Services for confirmation of the Fibromyalgia diagnosis. The Chronic Pain Management Service at Velindre Hospital and the Chronic Pain Management Programme (CPMP) referrals consist of approximately 30% of individuals with a Fibromyalgia diagnosis.

FUTURE DIRECTIONS

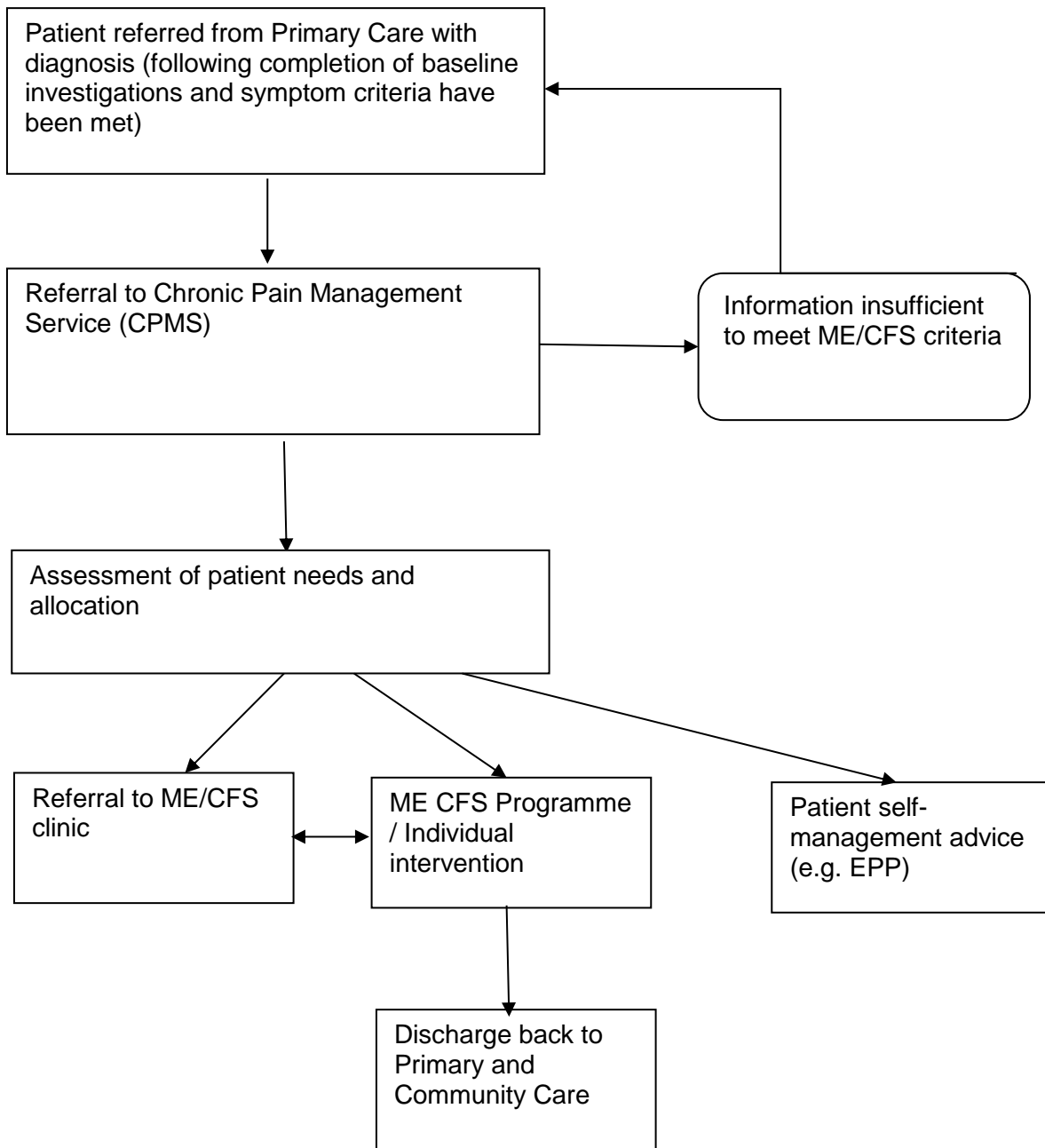
- Development of a Cardiff and Vale Implementation Group for ME/CFS and Fibromyalgia and identification of stakeholders and encouragement of partnership working with patients and providers.
- Education and raising awareness of ME/CFS and Fibromyalgia in order to promote identification and management of symptoms early.
- To advocate evidence-based approaches in the provision and equity of access to clinical services for people with ME/CFS and Fibromyalgia.
- Development and acceptance of ME/CFS and Fibromyalgia Pathways.

- Development of self-management using Prudent Healthcare principles and co-production values.
- To facilitate patient involvement to promote patient-centre care.
- To facilitate audit, outcome and bench marking evaluation of ME/CFS and Fibromyalgia in service provision.

CONCLUSION

The development of a Cardiff and Vale Implementation Group for ME/CFS and Fibromyalgia over the next 3 years will need to identify gaps within the current services, for example there is no identified specialist in ME/CFS and Fibromyalgia within Child Services and Transitional Care Services. The resource implications and challenges faced will need addressing as part of the future directions.

ME/ CFS PATHWAY



ME/CFS ACTION PLAN

	Objective	Action	Action Lead	Timescale	Progress
1	Health Board identify Executive Board Member to oversee pathway development	Meeting – Dr G Shortland / F Jenkins	Fiona Jenkins (Director of Therapies and Health Science)	August 2015	Completed
2	Health Board identify Clinical Lead (for ME/CES and FM)	Meeting (F Jenkins/Dr G Shortland/Dr S Khot/E Cooke/Dr J Hampson)	Dr S Khot (Consultant in Anaesthesia and Pain Medicine)	August 2015	Completed
3	Health Board identify home for ME/CFS and FM services	Meeting (Dr S Khot/E Cooke/Dr J Hampson/Dr B Jones/ N Griffiths)	Dr S Khot/ Dr B Jones (Consultant in Palliative and Pain Medicine)	October 2015	Completed Velindre Chronic Pain Management Service identified as home for ME/CFS and FM services
4	Health Board to identify specialists to establish stakeholder group (to support delivery of agreed pathways)	Identify member of Primary Care Clinical Board	Dr S Khot and CPM Service Team	July 2016	Ongoing
		Identify secondary care specialists (Rheumatology, Rehabilitation Medicine, Physiotherapy, Neurology, Endocrinology, Children Services)	Dr S Khot and CPM Service Team	July 2016	Ongoing
5	Health Board develop local pathways for ME/CFS and FM services	Pathway for FM adult service already in place. A pathway for ME/CFS service to be developed	 Dr S Khot and CPM	 October	 Ongoing

		(and agreed by stakeholders)	Service Team	2016	
6	Health Board to identify work to raise awareness of ME/CFS and FM diagnosis criteria in Primary Care (to ensure early implementation of pathways)	Stakeholder group to discuss	Dr S Khot/ Dr B Jones	October 2017	To be confirmed
7	Health Board to provide representatives to attend an All Wales Implementation Group (using shared partnership working)	Establish within Stakeholder group individuals to attend meetings	Dr J Hampson to attend next meeting	11 th November 2015	

Review Jan 2017