

## **Increasing resources and providing a support network for vulnerable transitioning adults with fibromyalgia/CFS**

The number of young adults diagnosed with fibromyalgia (FM), a condition of uncertain aetiology which caused widespread pain and fatigue and loss of productivity, is steadily rising. A particularly vulnerable group is patients transitioning from paediatric to adult services. Little is known about the prevalence of this group and what resources and support is available to them and their carers/parents in our local area. We wish to survey amongst local practices and the West Berkshire area

1. to establish a baseline number suffering with this condition
2. what their awareness of this condition is
3. what resources can they access
4. what their mental health and well-being is
5. what support has been provided to them and their carers

Estimates suggest that juvenile-onset fibromyalgia affects 2-6% of school children, mostly adolescent girls. It is most commonly diagnosed between ages 13 and 15. Since transition to adult services occur locally around the age of 17, it is unclear what support is provided, what general understanding exists of this condition and how the condition is often managed.

Many patients (up to 75 percent) will have a family member with a diagnosis of fibromyalgia. If recognised and managed early, the symptoms can improve. It is important to note that some patients, evaluated several years later, no longer experience enough symptoms to meet the criteria for fibromyalgia. However, this is a condition which seems to come and go throughout life.

We feel that people with FM need to pay careful attention to sleep, exercise, and stress levels in order to decrease symptoms of fibromyalgia. With careful attention to a balanced lifestyle, people with FM can live very happy and healthy lives with good quality of life and successful personal and professional lives.

There are good resources and support for adult patients with FM in West Berkshire and we wish to raise awareness of these resources for young adults. We also would like to evaluate the present demand for pain service support and the outcome of this project can help in increasing our resources to this area for our patients.

By accurately assessing the prevalence of this problem, we can tailor and improve resources and increase awareness amongst healthcare professionals and patients and their carers about self-management strategies and what they can access from the NHS in West Berkshire. With the diversity that is present, we can also ensure the relevant resources are culturally sensitive.

We anticipate that with the deployment of the above options, better use of the expert patient support group will be possible and local community engagement can be strengthened. We can also use a variety of methods to help these young adults occupationally, and help them lead more productive and successful work lives. Existing services both in primary care and secondary care can be improved and tailored to help this younger population both mentally and physically.

We aim to

1. Create an online survey requesting for response from Berkshire west citizens via local media.
2. Write to practice managers of all GP practices requesting for data relating to young adults 16 to 30 diagnosed with fibromyalgia syndrome
3. Once number identified, invite the group to complete a survey to understand their present understanding, awareness, support to carers and themselves, available resources and existing issues.
4. Develop both paper and online resources
5. Hold a workshop/roadshows through the county to provide face to face support and improve education and signpost services

QUESTIONNAIRE REGARDING HOW YOU HAVE BEEN AFFECTED BY FIBROMYALGIA/CHRONIC  
FATIGUE

**INTRODUCTION AND CONSENT**

We are from the Department of Pain Medicine at the Royal Berkshire Hospital and wish to conduct a service improvement project to improve our service for patient with fibromyalgia especially those that have been given this diagnosis and who are between the ages of 16 and 30 years.

We want to know how you are managing your condition and what support have you been made aware of or been provided by your GP or local hospital. It is hoped that the result of the finding will help us to plan and offer a better service and evidence based care for such patients much quicker and closer to home.

It will take only a few moments of your time and I hope you will find it interesting. Please do not write your name on the questionnaire as your confidentiality is guaranteed. Thank you for your participation.

For official use

Sign: \_\_\_\_\_

Location: \_\_\_\_\_



12. Do you feel confident managing your condition?

---

---

---

13. What would you like to know more about this condition?

---

---

14. Are you studying/working?      Yes                      not working                      not able to due to pain

15. Do you still socialise with friends?    Stopped now      1-2 times a week      more than 3/week

16. Do you have any previous history of anxiety/depression?                      Yes/no

17. Do you have any history of abuse or trauma in the past?                      Yes/no

18. Have you used any other recreational substances to help with pain, such as marijuana/cocaine/  
LSD/others? \_\_\_\_\_

## **KNOWLEDGE OF FM/CFS AMONGST FRIENDS/COLLEAGUES/FAMILY**

22. Do you belong to any patient support groups for your condition?

Online/Face-to-face/Other. If other please elaborate \_\_\_\_\_

If online, please provide name/s of group. Whether closed or open

If face to face, Details \_\_\_\_\_

23. Do your family/ friends/colleagues at your workplace understand your pain/condition? If no,  
what do you feel can be useful to make them understand?

---

---