Neurofibromatosis service: support for family and friends

This leaflet explains more about the support available for family and friends of people with neurofibromatosis (NF1 and NF2).

What support is there available?
As part of the development of the neurofibromatosis service, we are setting up psycho-educational groups for partners, relatives or friends who provide support and care for adult patients with NF1 and NF2.

Are the groups suitable for me?
If you are a partner, relative or friend of an adult patient with NF1 or NF2 who is registered with the neurofibromatosis service at Guy’s and St Thomas’, the groups are designed for you.

If you are a partner, relative or friend of an adult patient with NF1 or NF2 and you also have NF1 or NF2, a different form of support may be more suitable. We will be developing support groups/networks for people with NF1 and NF2 and if you would like us to contact you about this, please leave your details on the attached form.

What will we talk about in the groups?
The groups will be designed to help you cope with the challenges that caring for a person with neurofibromatosis can bring, and support your loved one in managing their condition. We will cover a number of topics including:

- stress management and dealing with negative emotions
- looking after your own physical health and wellbeing
- supporting patients to manage their condition
- supporting patients with medical procedures and appointments
- communication challenges and solutions
- changes in appearance
- how to access further support

What will the group be like?
There will be a maximum of 10 people attending the group. It will be run by a health psychologist accompanied by clinical nurse specialists working in the NF service. Each session will include informal discussion and group activities. There will be handouts to take away with activities to do between each session. There will be two separate groups for partners, relatives or friends of adult patients with NF1 and those with NF2.
Are there any drawbacks to attending the group sessions?
When you come to the group session, you may hear about and speak to people who are affected by NF1 or NF2 in a way that is different to your experience. This may be difficult for you and you may feel upset having learnt about potentially sensitive issues. These are normal responses and we hope that the benefits of meeting others will outweigh these concerns.

How long will the sessions last?
Each session will be 2.5 hours long and this will include 30 minutes scheduled to chat to others. Refreshments will be provided.

Where will I need to go?
The sessions will take place at either Guy’s Hospital or St Thomas’ Hospital. The location will be confirmed nearer the time.

When will the sessions take place?
The group will run every month for a total of six sessions. The dates will be confirmed once numbers for the groups have been set.

Will it cost anything?
There is no charge for coming to the sessions.

How do I sign up?
If you would like to attend, you will need to book your place in advance. There are a maximum of 10 places available for each group. These will be allocated on a first come, first served basis.

You can book your place in one of the following ways:
1) contact Dr Jess Walburn, health psychologist, at jessica.walburn@gstt.nhs.uk
2) complete the attached slip and put it into the box at the reception desk OR return to Dr Jess Walburn, Neurofibromatosis Service, Neurology Department, Guy’s Hospital, Great Maze Pond, London SE1 9RT
3) leave a message for Dr Jess Walburn by calling 020 7188 9976 (please include your name and contact details, and say that you are interested in the NF1 or NF2 family and friends support groups; please specify if NF1 or NF2).

I have more questions – who can I ask?
If you have any questions about the neurofibromatosis service or support groups, please contact Dr Jess Walburn, health psychologist, at jessica.walburn@gstt.nhs.uk or Neurofibromatosis Service, Neurology Department, Guy’s Hospital, Great Maze Pond, London SE1 9RT.

Useful sources of information
The Neuro Foundation is a useful source of information and support for people affected by Neurofibromatosis:
w: www.nfauk.org
t: 020 8439 1234

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<table>
<thead>
<tr>
<th>I am a friend or family member of a patient with NF1 being cared for by the NF service at Guy’s Hospital and would like to attend the <strong>NF1 family/friend support group</strong>.</th>
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</thead>
<tbody>
<tr>
<td>I am a friend or family member of a patient with NF2 being cared for by the NF service at Guy’s Hospital and would like to attend the <strong>NF2 family/friend support group</strong>.</td>
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<tr>
<td>I am a <strong>patient registered with the neurofibromatosis service at Guy’s and St Thomas’</strong> and I am interested in support groups for <strong>people with NF1 and NF2</strong> – please contact me when these groups are starting.</td>
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</table>

Please complete your contact details:

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Contact telephone number</td>
</tr>
<tr>
<td>Email address</td>
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<tr>
<td>Postal address</td>
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We usually contact people by email. Occasionally, we may need to contact you by telephone. To safeguard your privacy, please sign below if you give us permission to leave a message stating that we are from the Neurofibromatosis Service at Guy’s and St Thomas’ ringing about the family and friends support groups.

I give permission for you to leave a message as described above on the contact telephone number provided.

| Name: | Date: |