

## Volunteers

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1. The Guillain-Barré and Associated Inflammatory Neuropathies (**GAIN**) exists to support sufferers and their families, both in the acute phase of the illness and during rehabilitation, as well as providing continuing support for those with the chronic disorders which fall under **GAIN**'s remit. Support Volunteers are the charity's representatives for direct contact with those that request help from the charity
2. Those who wish to become a Volunteer should apply to the office for the necessary application forms and will be required to provide the names of two referees and a self-declaration form along with a photograph. Applicants may be required to undertake an interview and Disclosure and Barring Service or disclosure Scotland check. Successful applicants will be offered training and be provided with a comprehensive information pack to assist in their chosen role.
3. For insurance purposes, all Volunteers must be members of **GAIN**. Each volunteer will be issued with an identification card, bearing their name and a photograph, together with a contact telephone number for confirming their position; these remain the property of the Charity and will need to be returned on cessation of being a volunteer. All volunteers will be required to sign an agreement with the Charity before they can undertake their chosen role. Some volunteers may wish to be accompanied; for insurance and safe guarding purposes any accompanying person must have completed an application and signed the volunteer agreement.

### Role of the Volunteer

4. The Helpline volunteer is the initial link between the Charity and people with GBS, CIDP and associated inflammatory neuropathies, their families and carers. Time wasters thankfully are rare, but if one is received the volunteer should endeavour to keep such calls short. Occasionally the helpline may get a call for the office, and should recommend that the caller phones the office on 01529 469910 between 9am and 3pm Monday to Friday.
5. The Support Volunteer is to be the main link between **GAIN** and people with GBS, CIDP and associated inflammatory neuropathies, their families and carers. They provide support through their personal experience, tailored to the needs of the individual or family. Being a Support Volunteer can be a rewarding experience. Those who become Support Volunteers come from all walks of life, and bring a variety of valuable experience, skills and knowledge to the role. Support Volunteers have to be good listeners, who can deal with people sensitively and who understand the need for confidentiality. If required they may keep in regular contact either by visits, phone and/or email.
6. Volunteers should have the following qualities:

### Skills

- The ability to actively listen to others and show empathy
- The ability to support in a non-patronising way
- Volunteers must be IT literate

### Knowledge

- An understanding of GBS, CIDP and associated inflammatory neuropathies and the effects
- An understanding of the recovery process

### **Personal qualities**

- Patience
- A non-judgemental attitude
- Respect for others
- To be organised and committed
- Confidence to ask someone for help and advice if you are unsure

### **Requests for contact**

7. Requests come through a variety of means; through the internet, helpline, by post/telephone to the office and occasionally directly to a Support Volunteer whilst they are visiting another patient. This is to ensure that the Support Volunteer is covered by **GAIN's** insurance. If a Support Volunteer receives a direct request, the details must be telephoned in to the office in order that it can be authorised. In the event that a Support Volunteer is asked to see a patient and/or family while on a visit to a hospital, they should make initial contact and arrange a follow-up meeting. All requests **MUST** be recorded by the office before full contact is made. The office will send details of other requests to the relevant Support Volunteer for action using - secure email, "signed for" post or telephone. If a Support Volunteer is unable or unwilling to undertake the allocated task they must notify the office, within 5 working days of receipt, so the office can reallocate the task. Support Volunteers must not pass personal details of patients and/or families to other contacts without the agreement of the patient/family and authority from the office. **GAIN** is subject to the Data Protection Act and we must observe its terms which include using secure mail to pass personal data and not storing data on home computers. (See also paragraph 20)

8. As soon as a Support Volunteer has received a request he/she should get in touch with the patient/family. If a visit is required, the Support Volunteer must notify the office when they are visiting and also if they are to be accompanied. Prompt response and follow up after initial contact is very important. If this is not possible due to circumstances, please contact the office, who will arrange an alternative. The office will try and match the patient up with the most appropriate Support Volunteer to ensure that the advice and support given is suited to their situation and diagnosis.

9. Make sure the patient/family fully understand the purpose of a Support Volunteer. Discuss the purpose and extent of your involvement and time period over which it will continue. As we are invited guests of the patient, family or hospital, we cannot demand access to patients or families, so all visits must be pre-arranged with patient, family or hospital staff. Make sure you have planned sufficient time in your diary. It would look bad if at the first meeting you have to cut things short to dash to another appointment. Adopt an open, friendly attitude and encourage the patient to talk (if possible) openly and confidentially in matters relating to their condition. If a patient is unable to speak, but is otherwise alert, then tell them about your experience, if applicable, using blinking (1 for YES, 2 for NO) to facilitate dialogue. For additional communications, ask the nurse/and or a speech therapist for the most appropriate method, or if the patient is able, make use of **GAIN's** communication cards (available from the office).

10. Use the first visit to make clear in your own mind what support he/she is likely to need.

Record their personal details, if you have not had them before and give the patient, or member of the family, your phone number, so that they can contact you with any further questions. Ask if they would like you to keep in touch either by phone or another visit, and make sure you keep to any arrangement that is agreed. The office must be given advance notice of follow up visits. Support Volunteers must not visit without prior arrangement with the family, patient or hospital staff. If no further contact is required, then this must be respected (sometimes one visit or phone call is all that is needed).

11. In between visits you may want to keep in contact with the patient and/or family by brief telephone calls, but remember: don't talk too much, don't be dictatorial and always give your contact opportunity to speak, and listen to what they have to say. Complete a report after each call and further visit and send to the office via your secure email.

12. Most people want to know if they will make a good recovery and how long it will take. Do not lead people to believe that everyone makes a full recovery, because they do not. (Note, this is equally important when talking to relatives). If asked direct questions regarding time and chances of a full recovery refer the questioner to their consultant neurologist, although they are unlikely to give a definitive answer in virtually all cases. This aspect requires considerable sensitivity by the Support Volunteer and it is easy to be sucked into a potentially misleading answer which may cause considerable anguish at a later date. Say that most improve and are able to return to a normal lifestyle. Make reference to your own experience of illness and recovery. Also suggest that they discuss the rate and extent of recovery with the rehabilitation team, as well as the Consultant. Stress the importance of early physiotherapy to prevent unnecessary muscle wastage, as well the need to co-operate with the therapists at all times. Assure the patient that many GBS patients experience fatigue and that it is important to inform the nurse or therapist when they are feeling tired. Fatigue should be taken as a signal to rest. Answer all questions honestly within the constraints of NOT being medically qualified. Avoid physical contact, unless advised otherwise by the nursing staff.

## **RELATIVES**

13. Remember that the relatives are also in need of support. Be a listening ear for all concerned. Encourage relatives to become involved in the patient's care as much as possible. This will help the patient's morale and relieve the busy nurses. Relatives will benefit from contributing something, thereby feeling less helpless. Relatives should be encouraged to keep the patient in touch with the goings on in the outside world, to make their space bright with pictures and flowers (if allowed), read to them, bring in music etc.

## **REPORTS**

14. Reports should be telephoned or emailed using the secure email system at the earliest opportunity. For those reporting on the helpline, unless very urgent, the following morning is acceptable.

15. In order to provide full support, it is necessary to receive as much information as possible so please ensure that forms are completed accurately and with as much detail as possible.

## **ABSENCE/NON-AVAILABILITY**

16. Notify the Office of any changes of address, holidays and unavailability of any kind.

## **PUBLICITY**

17. Support Volunteers may obtain stocks of leaflets and posters for display in hospitals and GP surgeries. Full packs for medical professionals will be sent direct to a named person in the hospital or GP Surgery. Personal data, such as private telephone numbers or email addresses must not be provided or added to the posters or leaflets.

## **CONFIDENTIALITY**

18. Confidentiality must be maintained at all times. Volunteers must never give details of patients or families to any third party, including other Volunteers, without the consent of the patient/family. The Charity is subject to Data Protection legislation, and discretion is most important. The Charity also has a vulnerable persons' policy and volunteers should be familiar with it.

19. It may be useful for Volunteers to discuss cases they have dealt with, and this is acceptable, providing the identity of the patient/family is not revealed. If it is felt necessary to the discussion to reveal the identity of the patient, his/her permission must be obtained in writing before the discussion.

20. Volunteers may retain the personal details of their patients/families while they are still dealing with them, these must be stored in a locked container if hard copy or on an encrypted disk or in Dropbox and not stored on a home computer. Volunteers may apply to the office for an encrypted cloud storage folder. Once the case is closed all personal details and reports must be destroyed.

## **Some Dos and Don'ts**

### **Do.....**

- Arrange to visit in advance as you may be refused entry to the Ward
- Show you understand the patient's situation and problems they have but remember you are not the medical expert and advise patients or families to talk to the medical team.
- Create an informal atmosphere to put the patient at ease
- Show empathy wherever possible
- Be respectful of others views and opinions; avoid subjects such as politics and religion
- Remind patients and families that we have a personal grant fund they may wish to utilise
- Remember that you are acting on behalf of **GAIN**

### **Don't.....**

- Don't raise false hopes by making promises that cannot be fulfilled
- Don't get involved personally – keep a professional distance
- Don't get involved in personal issues
- Don't try to solve the patients problems – know your limitations and work with them
- Don't discuss individual patients with other volunteers.