



The Pituitary Foundation Helpline and Telephone Buddy Volunteer Handbook

A role specific handbook for volunteers
supporting the helpline and being part of the
Telephone Buddy programme

June 2023

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1 Volunteers on our Helpline or Buddy Programme

Our helpline and buddy services are in place to provide clear, accurate and unbiased information to patients, carers, friends, families, professionals and the general public. Our volunteers are delivering appropriate information to needs of the people using the service in a prompt way and to a high-quality standard.

Often, these services are also referring our service users appropriately to other organisations who can help meet the needs of the person calling.

Our helplines and buddy programme are our main way to directly support people living with a pituitary condition and has been running since 1998. We hear feedback from all over the country about how helpful these services are and want to thank you for being part of that.

This handbook is for Helpline and Buddy volunteers of The Pituitary Foundation as an easy reference guide about our services.

The Pituitary Foundation is a member of the Helplines Partnership. As such, our helplines comply with their guidelines for good practise (3rd edition). Our policy and practise reflect those guidelines and are included within this handbook.

Please read through this and the general handbook carefully and make sure you understand all policies. Whilst all content is important to give you the necessary information to volunteer, we need to make sure you've read all relevant policies before you start your role.

1.1 Role descriptions - June 2023

Our helpline staff will be asked to do at least one helpline shift a week. Shifts are 10am - 1 pm or 1pm - 4pm Mondays to Fridays.

Telephone Buddies' numbers are currently provided to helpline volunteers who pass on details to callers. Callers can then decide if and when to call a Telephone Buddy. **This procedure is currently under review and might be changed soon.**

In your volunteer role, you will provide appropriate information relevant to the need of each caller, providing emotional support where required.

Good listening skills are paramount to help identify exactly what the caller's needs are and to provide appropriate support during the call. Counselling is not provided from a Volunteer. Pituitary Foundation Helpline Operators or Telephone Buddies must not offer recommendations of clinics, medics or products, but offer choices where appropriate.

You will often need to assist the caller to work through some of the options open to them. Along the way, you should endeavour to empower the caller by providing good quality information and appropriate support to enable the caller to exercise choice and make decisions about their needs.

The role includes:	The role does <u>not</u> include
<ul style="list-style-type: none">• Listening• Informing• Supporting• Empathising• Guidance	<ul style="list-style-type: none">• Counselling• Advising• Telling• Deciding for the caller

<ul style="list-style-type: none"> • Reassurance • Suggestions • Selecting proven & appropriate information • Referring and signposting 	<ul style="list-style-type: none"> • Sending all information irrespective of caller's needs • Recommending or endorsing products or clinicians • Trying to solve all the caller's problems/dilemmas during one call
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1.2 Self-Disclosure Policy

Self-disclosure is when you disclose something about yourself to the caller. This may be requested by the caller e.g., "Do you have a pituitary disorder?" or at your own instigation. Either way you will be faced with choices of whether or not to disclose and how much if you do.

Why disclose?

This can be helpful to the caller to know that the person they are speaking to has a pituitary disorder. It can convey an understanding and perhaps acceptance of the caller's situation, so they feel less isolated and more encouraged to talk about their problems.

Why not disclose?

Self-disclosure can inhibit callers and take the focus from their issues. It may become easy to be self-indulgent, sharing experiences so that the call results in a chat and the mutual swapping of stories. It may also be frightening for the caller if they know very little about treatment e.g., pituitary surgery – your experience may sound daunting, if you disclose about this when the caller is not ready to hear about your experience. What you say as a Helpline Volunteer or Buddy could be construed as advice or recommendations simply because you have disclosed that you are a patient also and have experience or knowledge.

How to use self-disclosure appropriately

1. Establish a relationship with the caller. Do you know what it is the caller wants from you?
2. Why are you self-disclosing, and would this help the caller?
3. Be very brief about your disclosure, and return focus to the caller as quickly as possible.
4. Being over-positive may leave a caller feeling a failure for being negative or worried – their feelings should be validated and not swept away with breezy reassurances. The caller is coming from a different place to you; everyone's experiences are different.
5. You have the right not to disclose, and can choose what you are prepared to share. If you do choose not to disclose think about ways of deflecting requests for self-disclosure tactfully, as refusal may worry the caller you could be hiding something horrible (about the disease) or simply feel rejected. For example, if a caller asks about your experience, you could say:
 - a. "I'm here to help you, so let's focus on what's happening with you..."
 - b. "Yes, I am a pituitary patient, but all experiences are different, let's focus on yours..."

6. You may be having a bad day, so think about any issues of your own that may come across as less positive than would happen normally.
7. Colleague referrals – take care not to make personal disclosures about them. Make the referral on the basis that your colleague has experience, or knowledge of the issue under discussion.

What not to disclose

1. Never give the caller personal information about you: your address, home phone number, mobile phone number or personal e-mail address.
2. Do not give your last name or other general possibly identifying information, such as the town/city you live in.
3. Do not give callers the above information about other volunteers, members or staff. Use the charity's office contact information if callers want contact details:

Pituitary Foundation, Brunswick Court, Brunswick Square, Bristol BS2 8PE

Admin Phone: 0117 370 1333

E-mail: helpline@pituitary.org.uk

1.3 The Helplines' and Telephone Buddy Confidentiality Policy (reviewed 2022)

All staff and volunteers are bound by The Pituitary Foundation's Confidentiality and Disclosure Policy. Before serving the Helpline or Buddy programme, you should have read and signed The Foundation's Confidentiality Policy, keeping one for your records and sending one to the office to have on file. The following policy is in addition to the general Confidentiality and Disclosure Policy to cover for the situations you will come across as part of your volunteer experience.

The Helpline and Buddy Programme Confidentiality Policy

Anyone who contacts the organisation will have their personal information treated with respect and in confidence.

The Principle

Information considered confidential by The Pituitary Foundation is as follows:

- all information about its individual members, supporters, service users, volunteers and staff;
- information regarding donors, benefactors and sponsors (unless expressly excluded by the organisation/individual concerned);
- some aspects of The Foundation's internal affairs such as finances, staffing details, organisational matters, etc.

How the Helpline Service keeps information confidential:

Helpline Operators will treat with confidence personal information about users, whether obtained directly or indirectly. This information includes names, addresses, medical details and any other circumstances, which might result in identification. Information is held only for lawful purposes which are described under the Data Protection Act 1998 (page 12).

Information will be used or disclosed only for the purposes agreed with the caller, except where the user or third party are at risk of harm. (See our Safeguarding policy).

Operators are at liberty to speak with colleagues (staff and other volunteer operators) about Helpline calls for information or debriefing purposes. Casual conversations about callers are discouraged. Discussion about callers with those external to The Foundation is strictly prohibited.

If a return call is requested by the caller, it will be assumed that implied consent has been given by the caller for messages to be left with a third party if the caller cannot take the call personally. This includes answer phone messages.

Information should only be sent to the individual who makes a request, even if it is requested on behalf of someone else.

Personal details (e.g. address and telephone number -including mobile) of any staff member, Helpline Volunteer or other volunteer should not be disclosed to a caller unless permission has been given.

All letters, notes and call record sheets should be kept in a locked cabinet or drawer when not being worked on. Letters and notes must be disposed by shredding. Call record sheets should be remitted to the charity's main office via email.

If a Helpline Operator or Buddy knows a correspondent personally he/she will not respond to the letter/email, but will pass on to a colleague to reply.

There are instances when you will be obligated to break confidentiality. This would only arise:

- If a caller has indicated they are involved in terrorist activities, this must not be kept in confidence under any circumstances. The operator is obligated to report any such instance, with urgency, to the Head of Support Services.
- If the caller mentions that they themselves are at risk of suicide.
- If the caller is experiencing abuse or harm, or there is a risk of further harm. The operator is obliged to report any such instance to the Safeguarding Officer.

1.4 Important Information to Start

Prepare for Your Shift

To prepare for your shift, be certain that you are able to take calls in an area where you feel comfortable and you have privacy. If you are at home, and you have others with you, let them know you will be taking Helpline or Buddy calls and the length of your shift.

There should be as little background noise as possible and you should have no distractions.

It is essential to provide strict confidentiality to the callers, so if others can overhear you during a call, you should choose an area with more privacy.

It's important to be focussed on the caller and their needs. Therefore, although you don't have to sit waiting for the phone to ring, be certain you can set aside any tasks you are doing and concentrate solely on the call.

Standard Greeting

The operator's greeting could be the caller's introduction to The Pituitary Foundation, so

be focussed and pleasant. When the phone rings, take a moment to take a deep breath and clear your mind, even if this means the phone rings two or three times.

For continuity and best practise our opening welcome to a caller should be:

“Good morning/Good afternoon, Pituitary Foundation Helpline, (your name) speaking.”

Or, as Buddy: *“Good morning/ Good afternoon, [insert name], Telephone Buddy from The Pituitary Foundation speaking”*

The caller at first may find it difficult to know what to say and could be upset, you could start with:

“Would you like to tell me a bit about your situation?”

Your values and beliefs

Your values and beliefs are an integral part of you. However, in your volunteering role you should not share your own opinion, lead a caller in a particular direction, or say what you would do in their situation. These responsive are being directive.

Instead, helpline volunteers should be non-directive.

Being non-directive means:

- Enabling callers to make their own choices
- Being aware of how your own beliefs and values might influence the call and ensuring these are put aside
- Not telling callers what to do
- Giving information and not personal advice

1.5 Referrals and Signposting

There may be times when you will not be able to answer a query or the caller may ask more specialist information. If you do not know the answer to a question, it does not reflect on you. The important thing to remember always is that the caller receives the appropriate information and is able to find the help they need.

This may mean you'll need to refer to someone else, another organisation, a medical professional, another volunteer or a member of staff. Below you will find some information about types of referrals. Please also see the last pages of this handbook for our resource list.

Internal Referrals

Internal referrals are to staff members, the endocrine specialist nurse service, Trustees, support groups, other Helpline Volunteers or Telephone Buddies within The Foundation or direction to our website.

When referring internally, you should guide the caller's expectations. Explain that, as a charity, we have limited staff and volunteers and many of our services have scheduled hours. For instance, the Endocrine Nurse Helpline is available only during specified hours during the week and the caller should only phone during those hours. Furthermore, with these limits on service, the nurse might be quite busy during shift and the caller may get voicemail. If the caller knows what to expect, they will be less likely to be disappointed should they meet with obstacles. However, do reassure the caller that their concerns are important to us and we will do our best to be responsive to them.

Some things you can say:

“I’m afraid I don’t know that much about test results and many clinics have different ranges for what is normal and what isn’t. I think it would be better if you talked to The Pituitary Foundation’s Endocrine Nurse. Do you have a pen and paper handy? Her number is... and she takes calls... We ask that you please call her only during these times and remember she is quite busy. So, if you get her voicemail, try calling her again later or on another day.”

“I’m sorry, I don’t know very much about benefits. But we do have a telephone buddy who does. His name is Howard. Do you have a pen and paper handy? His number is... he likes to get calls during the times of... Please remember, he’s a volunteer doing this on his own time so it might be difficult to contact him or he might be in the middle of something when you call. But he is happy to get your call and will do his best to answer your questions.”

Using Our Website

Our website has the most accurate and up-to-date information. All our medical resources are checked by professionals. You should ensure that you are using information directly from our website, rather than notes or information you may have yourself, or have gathered over the years. This is to ensure the information being shared is accurate.

You can read out information on the website (if the caller doesn’t have access) or give the caller the link to the information they are enquiring about.

External Referrals

External referrals, known as ‘signposting’, is pointing a caller to outside organisations that are expert sources of information that you, or The Foundation, may not have.

The Pituitary Foundation does not make recommendations and does not share the names of particular endocrinologists. We have some information about centres which have endocrine departments but cannot offer further information. The Pituitary Foundation has a specific section on the website, which contains information which you can use to help you signpost to the correct organisation.

Please only signpost callers to reputable organisations that offer reliable service.

At times, it is necessary and acceptable for you to refer the caller back to their GP, endocrinologist or endocrine nurse.

As you will see from the examples above, when giving either Internal or External Referrals, it is good practice to ask first if the caller has a pen and paper handy. After you have offered the information, to make certain the caller has taken down the information correctly (so as not to waste their time in following through with the signposting or forcing a repeat call) repeat it, for example, “Let me make sure I gave that to you correctly... [repeat the information].”

1.6 Support for you

Uncomfortable, distressing or negative calls can be received or happen through no fault of the Helpline Operator or Telephone Buddy.

On these occasions, we do suggest and welcome that you debrief with the Head of Support Services, Endocrine Specialist Nurse, Volunteer Coordinator, another Helpline Operator or Telephone Buddy. If you have any concerns, don’t feel well or feel uncomfortable about a phone call or situation, please contact the Head of Support Services or Volunteer Coordinator.

Alternatively, some calls may bring positive or exciting news or feedback that you are also very welcome to share.

1.7 Examples of Possible Call Scenarios

The below are examples of call scenarios and how to deal with them. For difficult scenarios, refer to the Decision tree which is attached at the end of this document.

1.7.1 How to guide an undiagnosed caller

- Listen.
- Suggest they visit their GP and explain their symptoms fully; suggest they take someone with them, and to jot down relevant symptoms and dates they began.
- If their GP says their symptoms don't relate to a pituitary problem then the caller should ask what other cause is possible.
- Advise the caller of The Pituitary Foundation's relevant patient booklets e.g., the Pituitary Patients Handbook (a packet of these will be made available to you for reference). Please see the section on Booklet Orders in this Handbook.

1.7.2 How to guide a newly diagnosed caller

- Listen – the caller may be anxious/distressed and seeking reassurance.
- Ask if they have seen an endocrinologist yet. You may have to explain what an endocrinologist does if they are unsure.
- Ask them if they have Internet access and refer them to our website. If not, offer to send (via the office) the relevant booklets. Be certain to suggest any relevant booklet, e.g., if surgery is imminent, offer Pituitary Surgery & Radiotherapy booklet.
- If asked by caller “Are you a patient?” calmly disclosing can be helpful but only if you are comfortable doing so.
- Reassure realistically about their next steps e.g., tests – there can be some time between scans, tests and appointments (this can be frustrating but is common), admission to hospital for surgery, approximate timing of inpatient stay (anywhere from 4-7 days), recuperation (some people feel fairly well after a couple of weeks, others may take a little longer to feel more themselves and have any replacement hormones balanced). Explain that they may feel quite tired after surgery; that there can be varied timings of returning to employment, depending how the individual feels (if appropriate).
- Offer ongoing support through their journey and welcome them to call at any time during Helpline and Buddy hours.
- Offer access to other Foundation support including Helpline/Telephone Buddies, Local Support Group in their area, Endocrine Nurse Helpline, our website.

1.7.3 Negative or distressing call

Certain calls may leave you angry, depressed, or frustrated that you can't help the caller more.

You may find certain callers very difficult or draining to work with. Sometimes your own experiences can be reawakened after a difficult call.

There will be a minority of callers that whatever is offered or suggested will not be acceptable, and can be particularly negative or hostile.

Our policy is that you have support following a call like this if you require it. We recommend that you phone a member of staff as it often helps to offload before continuing with other calls.

There is a small possibility that you might receive a call which is inappropriate or causes you some uneasiness, e.g., is aggressive, bullying or inappropriately sexual. Our policy is not to judge callers, their lifestyles and beliefs or their reactions to situations and needs. We ask that you do your best to be supportive but if you feel there is a cause for concern about a caller, please report it to the Head of Support Services as soon as is convenient.

For further actions, please refer to the Decision Tree attached to this handbook.

These types of calls may include the 'repeat caller':

- Listen.
- It may be difficult to respond or interject throughout the call due to the caller either maintaining a stream of statements, or they simply block your responses with a negative reply, e.g., "I've done that, it didn't work."
- Gauge that anything you have offered by way of reassurance, empathy or suggestion is not working with this particular caller.
- Say to caller: *"I'm sorry that on this occasion I don't feel I'm able to help you any further."* You can offer the option of the Head of Support Services calling them, if they'd like you to give their number – and give a reasonable timeframe that this will happen.
- Close the call (stand up if necessary) – *"Thank you for calling; I do hope you feel better soon/ you will receive the information you require from the Head of Support Services. Goodbye"*

1.7.4 Important things to remember

- Always listen – if you are talking more than the caller, you are not supporting them.
- Give yourself a break, especially after long or distressing calls.
- Call a member of staff or another volunteer to debrief if you feel upset or frustrated by a call.
- Remember that each call may be one in many for you, but the call will be very important to the caller so you must do your very best to be appropriate in your response, your manner and the information you provide.
- If you are tired, feeling unwell, or simply having a bad day don't hesitate to ask a member of staff to take your shift. We are here to support you.

1.8 Types of Calls and Callers

1.8.1 Someone Experiencing Adrenal Crisis

An adrenal crisis is a potentially life-threatening situation.

If you understand that the call is experiencing an adrenal crisis, you should advise them, or someone with them to call 999 and say that the person is 'having an adrenal crisis'. That they are 'steroid dependent and need medical help for im/iv hydrocortisone'

If patient is really poorly and unable to do this (if they tell you or operator realises they are unable to) ask if you can have their permission – name (if not given already) phone number and address – pass this to Pat and she can contact ambulance.

If they are in hospital and being denied hydrocortisone:

- 1) Ask the patient (or their family or support if they're not able to) to ask ward staff to contact the endocrinologist on call
- 2) Suggest they call their endocrine team if they are within a different hospital
- 3) If patient is not getting help with step 1) or 2), take the name of the patient and the hospital/ward they are in and call Pat or the nurse helpline if they are on shift to speak to the Nurse in an emergency - 0117 370 1315 / Mobile 07540 298863

***Adrenal crisis symptoms include:**

- **Feeling weak, faint, dizzy**
- **Feel nauseous or want to vomit**
- **Abdominal pain**
- **Shivering, feeling cold but clammy**
- **Headache**
- **Muscle weakness**

1.8.2 For inter current illness/ general illness unrelated to their pituitary condition (non-crisis)

If a caller calls with an inter current illness (e.g., tonsillitis, appendix, flu etc.), ask caller to phone 111 or their GP surgery for an urgent appointment. Caller to state to GP receptionist 'adrenal insufficiency/steroid dependent/ AVP-D'.

If caller is clearly unwell but able to keep tablets down and hasn't taken any extra HC, advise of sick-day rules for increasing HC dose, before they go off phone to call GP.

It is acceptable to advise the caller to take extra hydrocortisone there and then, as our nurse has stated **it will do them no harm** in the short term but could prevent a more serious incident/adrenal crisis occurring. Advise them to follow up with GP/medical appointment as soon as possible afterwards.

1.8.3 Calls from people at risk of self-harm

There may be (rarely) a call from a person who is talking about committing suicide, or you feel is about to commit suicide. Under the Helplines Partnership guidelines, legally, we have no obligation to seek further help for this type of caller, as difficult as that is for you as the call taker - but please see below for exceptions that we make.

We advise that you proceed with the call in a supportive and caring way (as usual); your actions (or non-actions) would have no effect on the caller's choices, and you have no responsibility to change what they may (or may not) attempt. It is appropriate and recommended that you suggest, if a caller tells you they are thinking about committing suicide, that they contact The Samaritans 116 123 www.samaritans.org This is an organisation that is set up to provide emotional support and they are trained to help callers through these times.

However, you can contact a staff member to talk through the call and we will support you and advise further where necessary.

***Please Note:** The Pituitary Foundation boundaries on suicide calls cover the following two scenarios only. If either scenario occurs, it is vital that you let a staff member know

immediately, giving as much information as you can, such as: callers telephone number (if displayed, or given), area the caller is from (if given) plus time and length of call.

- The caller tells you, or you (the operator) are aware of any immediate and obvious danger to any infants or children within the care or company of the caller, during the call.
- If the caller has disclosed that they have a weapon on them and has said this weapon would be used to harm others (and then to harm him/herself)

1.8.4 Bomb Threats, Warning & Terror Alerts

Although rare, Helplines could receive bomb threats and terror warnings. **ALL** such reports must be passed to the police or security services, immediately. Under the Terrorist Act we are legally obligated to disclose (and break confidentiality) information related to terrorism

Helpline operators should make a note of the time and duration of the call. Attempts to establish the target and time of the threat should also be made. Operators should record any information, and pass it on to Pat or Endocrine nurse, or CEO, and they will contact the relevant agency (police; security services; etc.). This includes information that may seem inconsequential, such as any code words given. If possible, everything said should be recorded verbatim.

Example threat Procedure

When a threat is made:

- Note the exact date, time and duration of call
- Obtain as much information as possible:
 - Is the caller an adult?
 - Type of accent, male or female
 - Take note of the caller's knowledge of any mentioned building, street or place
 - Calmly notify the supervisor immediately (Pat McBride) and follow their direction.

Please note we have never received any calls of this nature and it is not meant to alarm, simply a sensible guide for you to be aware of.

1.9 Closing a Call and Calling back

Closing a call

Most calls naturally come to a satisfactory conclusion for the caller within a reasonable time. Some calls can last only a few minutes whereby the information the caller needs are quickly available. Some calls may be lengthy but will warrant this time to best support the caller. On occasion, calls can last up to an hour but, if appropriate for the call, you should be searching for a satisfactory conclusion before this time.

If a call is continuing extensively and not appearing to satisfy the demanding caller, or you are finding it difficult to continue due to their manner, or negativity - briefly summarise the information you have given or received during the call to bring the call to an end.

You are not rejecting the caller if you bring matters to a close, as long as this is done in a supportive way. Make it clear that they are welcome to call in the future.

On the very rare occasion, you will realise through the conversation that the caller will not accept or acknowledge the support we offer. It is appropriate and recommended to advise the caller that the Head of Support Services will call them and write down the caller's number. Close the call as soon as possible and phone or email the Head of Support Services to report the call.

It is good practice to be certain the caller understands they are invited to call back on the matter at hand, or should they need any other information or support.

A good tip to help you close a call is for you to physically stand up from your chair, whilst speaking to the caller, as this prompts you to take control, without being rude.

Calling the Caller Back

Recently, our helpline telephone system has in place an automated message which the caller hears before speaking with you, which states 'Please do not leave a message as we cannot call you back, but please try again if line engaged.'

In normal circumstances, we do not contact callers. If you are working from a home telephone, you should not call callers back but refer any needed call backs to the office. We can also email them with information if you can take their email address.

If you do have to seek information on behalf of the caller as helpline volunteer, firstly dial 1471 before the number to retain your privacy. Please let the caller know what sort of timeframe you, or someone else from The Foundation, will be calling them back e.g., *"I'll ask that our Foundation Administrator to call you by tomorrow afternoon"*.

If calling back, be aware that the number given may be a work number, a household number or their answer phone. To retain the caller's confidentiality, it's best to say (if the caller doesn't pick up):

"Hello is John there?"

-"No he isn't in at the moment"

"Could you let him know that Jane returned his call, and I'll call back later?"

Or for answer phone message:

"Hello this is a message for John; it's Jane from The Pituitary Foundation, returning your call, please contact me when convenient - thank you."

The main Helpline number has a permanent block so people can't return the call by pressing 1471.

1.10 Endorsement

The Pituitary Foundation does not recommend, endorse or promote any products, treatments, consultants or companies. Nor do we offer a negative judgement on a product or person. If it is appropriate to suggest, for example, a travel insurance company, it is best to offer details of more than one company.

It is reasonable to expect a caller to want the name of a reputable endocrinologist or neurosurgeon. In these cases, it is our policy that operators provide information to the caller's closest centre(s) of pituitary excellence, a list will be provided to you. Refer the caller to their GP for further information and a referral.

If the caller persists in asking for a name, or perhaps they wish you to divulge your consultant's name, or a consultant you personally have heard of - please be very careful of endorsement and use only the personal experience you have. For example, if the caller lives in the Birmingham area, and you are a patient there, or may know of another patient at the Queen Elizabeth II Hospital (a centre of pituitary excellence) you could offer the name of the hospital and the names of the endocrinologist there. The caller's GP can then instigate any referral as appropriate.

1.11 Professional Indemnity Insurance

To adhere to our Professional Identity Insurance, it is vital that staff and volunteers do not offer advice, and that the support offered should be taken in conjunction with medical advice from the callers GP or endocrinologist. If the Helpline Operator or Telephone Buddy gives callers information, advice or signposts on which the caller may rely on to make significant decisions - and those decisions involve expense or distress, for which they might want to recover damages or costs against The Foundation - The Pituitary Foundation does carry professional indemnity insurance and keeps records about the policy within the Office.

To avoid such a situation, it is important to remember that the confidentiality of the caller should be kept intact and that you make no recommendation or endorsement. However, if a caller brings to your attention that there is an issue with something you may have noted, please bring this to the urgent attention of the Head of Support Services.

1.12 Media Enquiries

Media related enquiries might reach you through the Helpline or Telephone Buddy Service. These include:

- TV and radio journalists
- Newspaper editors
- Magazine journalists

These enquiries should be referred to Pat McBride. Therefore, please take a message with their name, the organisation they work for and the matter on which they are calling. Assure them that they will receive a prompt response and suggest, in the meantime, they might find a wealth of information on our website and also, it may speed up the process if they submit any questions in writing by emailing them directly to the Head of Support Services - pat@pituitary.org.uk At your earliest convenience, notify Pat that there has been a media query, providing the information requested above.

It may be tempting for you to try to answer any immediate questions from a journalist, but to ensure that this does not place The Foundation in a vulnerable, misquoted or inappropriate position, it is best not to enter into any conversation. However, do remain confident, calm and helpful.

1.13 Call Record Sheets – for Helpline volunteers only

An online call sheet should be completed for each call. The purpose of this sheet is to record information about the caller, which enables us to record how people access our service. If the caller requires further information sending, a full postal address should be taken, with their permission. 'Permission' is implied consent, if the caller freely gives details such as: address; age; occupation; condition; hospital; telephone number; email address. The sheets can also identify if the caller would be interested in future publicity and awareness raising, volunteering or membership.

It is best practice to complete your call record sheets as soon after the call is finished as is feasible. This will mean the information is fresh in your mind as you complete the sheet. All call sheets must be sent before the end of each month as the spreadsheet call stats are prepared in the first few days of each month. For example, if you take a September 30th shift, we would need the call sheets by the first week of October.

Please take all reasonable measures to keep your completed call record sheets confidential. If you are a volunteer working at home, these sheets should not be kept on file. After you are certain that Kim Wegner, Volunteer Coordinator has received your sheets, any notes should be shredded (if you have taken notes) or deleted from your sheets on your computer within a few weeks. On the very rare occasion that you might receive what is an obvious hoax caller or a 'silent call' it is still necessary to log the details of these types of call. Again, if you are concerned about a call like this, please do contact a staff member to discuss.

2 Decision tree

This decision tree directs you towards actions that you can take when dealing with difficult callers.

Type of call	Actions
<p>Diagnosed – regular caller (may have anxiety) Traits:</p> <ul style="list-style-type: none"> ▪ Repeat calls to all Helplines ▪ Same info given but not taken in ▪ Can become dependent on one vol or nurse 	<ul style="list-style-type: none"> ▪ Explain service remit limits and if mental health issues mentioned, or long-term anxiety, signpost to Mind etc ▪ State we are here for practical support but this is within pituitary day-to-day living for helpline /medical queries for nurse line ▪ Remind of other callers waiting to get through – limit call 10 mins <p>Trigger: If calls continue note any name given and number - caller care plan</p>
<p>Undiagnosed, insists has pit condition Traits:</p> <ul style="list-style-type: none"> • Repeat calls to all Helplines • Doesn't listen, talks over call taker • Ignores any links given, or has seen them • Commonly says GP won't help or endocrinology say no diagnosis 	<ul style="list-style-type: none"> ▪ Explain service remit - we cannot diagnose patients but offer signpost to our resources for condition information. ▪ Remind of other callers waiting to get through and have to close call <p>Trigger: If calls continue note any name given and number - caller care plan</p>
<p>Angry, abusive caller Traits:</p> <ul style="list-style-type: none"> • Repeat caller • Usually undiagnosed/ no pit condition 	<ul style="list-style-type: none"> ▪ State quickly that we don't tolerate abuse or bad language (if used). Say I'll have to close call if this continues.

<ul style="list-style-type: none"> • Not looking for support, just reaction 	<p>Please call us again when calm and if it is related to a pituitary condition</p> <p>Trigger: if abuse continues, note number, any name given and put phone down</p>
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Caller care plan

- Gain ID of caller (ask agreement with caller i.e. name, number) if not agrees, we can note this anyway for call handler care reasons.
- Note challenging caller, agreed process of care plan put in place
- This plan includes **times they can call, how long the call is limited to, topics that can be discussed**
- They agree or not at their next call of these plans in place
- **All** call handlers follow plan

3 Information and Resources for Referrals and Orders

3.1 Pituitary Website

Website - www.pituitary.org.uk

You should familiarise yourself with The Foundation's website and have it active on your computer while you are on a Helpline or Buddy shift. Remember, however, that it might be upsetting or offensive to a caller for them to hear you tapping away on a keyboard. You could say, "Bear with me; I'm looking something up for you on the computer."

Our information is primarily available on our website. Our website is accessible (people can adjust how they view it to make it easier to read), and the information is checked and accurate. Most website pages can be printed off, but we also have booklets available. These are:

- Acromegaly booklet
- Cushing's booklet
- Diabetes Insipidus awareness card - Free resource
- Diabetes Insipidus booklet
- Diabetes Insipidus toilet access card- Free resource
- Employment booklet
- Growth hormone factsheet
- GP Fact file (for health care professionals)
- Hydrocortisone advice for parents leaflet - Free resource
- Hydrocortisone advice pituitary patient leaflet - Free resource
- Hydrocortisone awareness card - Free resource
- Hydrocortisone care guide for schools - Free resource
- Hydrocortisone factsheet for ambulance personnel - Free resource
- Living with infertility booklet
- Male hormones and infertility issues booklet
- Pituitary Foundation poster - Free resource
- Pituitary gland booklet
- Pituitary Life magazine

- Pituitary patient care card – Free resource
- Pituitary patient handbook
- Pituitary surgery and radiotherapy booklet
- Post pituitary surgery fact sheet – Free resource
- Prolactinoma booklet
- Psychological impact of a pituitary condition booklet
- Referral pads (for health care professionals) – Free resource
- Relationships and communication booklet
- Weight control and nutrition booklet
- Your journey booklet

We have a selection of free resources which a caller may want to order. This can be done via the website for a small fee to cover processing and postage costs. If the caller is not comfortable ordering online, please ask them to call the office on 1007 370 1310.

Local Support Groups Details of our local support groups are on our website. There is an enquiry form for each one. Our groups are run by brilliant volunteers and operate in slightly different ways.

Note that volunteers running support groups should not be taking support calls, these should come through the helpline to trained volunteers.

Telephone Buddies Network

Again, our Telephone Buddies are volunteers and their details should be disclosed only as they have given permission.

Patient Information & Support Helpline

The opening hours can be found on the website. Be certain to advise on the scheduled hours to manage the expectations of the caller.

Endocrine Nurse Helpline

The opening hours can be found on the website. Be certain to advise on the scheduled hours to manage the expectations of the caller.

3.2 Endocrine Centres

You can find a list of Endocrine Clinics across the UK and Republic of Ireland that are considered ‘Centres of Excellence’ as part of volunteer documents made accessible to you. When possible for the patient’s travel needs and location, The Pituitary Foundation may offer endocrine consultants who practice in pituitary Centres of Excellence.

3.3 GP Referral

If you receive a call asking about a patient wanting their GP to refer them or gain a second opinion this is our policy:

- The patient has the right to ask their GP for a referral, (or may be termed as a second opinion) – either on the NHS or by a private consultation
- There is no absolute right to a referral, or a second opinion from a GP but it would be unusual for a GP to refuse such a request

The GP may not wish to refer a patient, for example, if they felt that the further testing involved may cause more harm to the patient than they deem necessary.

Most referrals would usually require a letter of referral from the GP, even those wishing a private consultation.

3.4 Endocrinologist Second Opinion

If a patient has been seen by an endocrinologist but wishes to see a different endocrinologist, the usual process is:

- Patient speaks to GP for his/her help in finding another consultant, or is given name(s) of appropriate pituitary specialists from The Foundation clinic list, if requested and takes this information to GP
- GP arranges an appointment with new consultant via referral letter and works with original consultant to exchange relevant reports, scans and pathology to new consultant

3.5 Medical enquiries

If you are asked about medical queries, such as blood tests, results, scans etc, refer the patient to our Endocrine Nurse Helpline. Let the patient know that you aren't able to advise/help with these queries but our endocrine nurses can.

3.6 Prescriptions

If you will have to take hydrocortisone, thyroxine or desmopressin permanently you will get free prescriptions for all medicines. Patients can ask at their GP's surgery, hospital or pharmacist for form FP92 (EC92A in Scotland). The form (which will need to be signed by your doctor) tells you what to do. You will then receive an exemption certificate. These certificates only last for a finite period after which they must be renewed. Your health authority may automatically send out an application for renewal.

Information about free prescriptions and the full list of medical conditions which qualify for exemption from prescription charges can be found in booklet H11, available from pharmacies and main Post Offices or on www.dh.gov.uk. If you are not sure whether you are entitled to free prescriptions, you must pay for your prescription and ask for an NHS receipt (form FP57 in England, EC57 in Scotland) when you pay; you can't get one at a later date. This form tells you how to get your money back. You must claim within three months of paying.