

## Section 4

### Guidelines and Procedures for Helpline Volunteers

#### Helpline 0808 802 8000

Our helpline is undoubtedly more effective through the involvement of our volunteers who have either personal or professional experience of cervical cancer or cell changes (abnormalities). It is also rare for a helpline to have this wealth of experience which makes it special.

Jo's Cervical Cancer Trust is a member of Helplines Partnership which advises, supports and sets out standards and a code of good practice for helplines. Helplines Partnership stipulates that member helplines must meet certain criteria to qualify for membership. These include a confidentiality policy and complaints procedure, copies of which are set out in Section 2 of this manual. By working to these standards, callers may be assured of a consistent high quality and responsible service.

In addition Jo's Cervical Cancer Trust was awarded the Investing in Volunteers Standard accreditation in January 2015 and successfully renewed the standard for all of our volunteer roles in 2019. This standard ensures that helpline volunteers can carry out their demanding roles under measurable and reasonable conditions, and receive appropriate training, support and supervision. Furthermore, potential funding agencies will recognise this standard, alongside our Helplines Partnership membership and be assured that our helpline offers a high quality service and is worth funding.

**It is important, therefore, that you read and observe all the guidelines in this manual – they are not optional or negotiable. If you have any comments or queries about anything in here, please contact the Support Services Manager to discuss the issues.**

#### Opening hours

The helpline is open throughout the working week, covering most days and evenings, according to the availability of volunteers and staff. The times and dates are worked out in advance on a rota. We also offer limited opening times at weekends.

#### The rota

The rota is made up in advance for one month and the details advertised on our website in blocks of two weeks. Towards the end of the one month period, the Support Services Officer will ask which dates you can comfortably do for the next month. It helps us for you to put down any availability you have so that we have more options to choose from for your shifts. If there are any dates not covered, a second email will be circulated to see if more cover can be found.

You are responsible to be on duty for your shift you have volunteered for. If there are changes that need to be made through ill health or other unforeseen circumstances, please let us know as soon as possible. It is a good idea to note your duties somewhere visible to remind you and anyone else who might take care of you if you are suddenly unwell. Missing or forgetting your shift means that callers may try to use the service as it has been advertised

as open. It is important that the service is reliable therefore, if you need to set a calendar reminder or an alarm to remember your shift, please seek to do so.

### **In an emergency**

If you are unable to cover your shift on the helpline, please let the charity know as soon as possible at the office in the week (9 – 5pm) or outside office hours directly to the Support Services Manager on 07984885884. For outside office hours, if you are unable to get through to her initially, please leave a message or send a text message and she will return your call as soon as possible.

### **Holidays**

Do let the Support Services Officer know as soon as you have booked a holiday so that this can be taken into account when the rota is being organised, and we know when you are not available for cover.

### **Covering for other people**

Although we try to keep this to a minimum, there may be times when you are asked to do extra duties at holiday times or to fill in if someone else is suddenly ill and unable to do their shift. We are always grateful when people do this but understand if you are not able to.

### **Logging sheets**

In order to show our effectiveness as an organisation, it is required that you complete an online logging sheet after each call. The information should be in general terms so not to breach our confidentiality rules.

*\*\* see our general confidentiality policy in section 2 of this manual.*

The logging sheet is initially question led and gives us a general picture of our callers. With the data, apart from the obvious head count, we can use it to keep our frequently asked questions (FAQ) on our website fresh and ensure that our Health Information and Engagement Department is providing information that the cervical cancer community needs.

This data also allows us to see the optimum times for the helpline which may help with future plans for coverage. The age group of callers may influence how we bring awareness of cervical cancer/cell changes or prevention to others. Understanding whether callers have used any of our other services, how they were diagnosed, treatment they have received, and how they got the helpline number all helps our future work. Understanding the ethnicity of our callers tells us if our outreach work is allowing us to reach and support people from many different communities. These are just a few things to highlight that the information you give us is crucial and helps us in delivering the best service we possibly can to our callers.

The information we are seeking to get is essential for the improvement of our service. Much of the information you are asked to fill in about the caller will often come up during the call. If it hasn't, ask them at an appropriate point during the call without disrupting the flow. In a lot of cases, this can best be done at the end of the call. In our experience, callers rarely mind being asked and understand the benefits of the questions.

Our logging sheets are digital and can be accessed online via The Volunteer Hub on the Jo's Cervical Cancer Trust website. The Data Protection Act controls how personal information is used and stored by organisations, businesses and governments. Everyone responsible for using data is required to follow strict rules called 'data protection principles' including charities. This means that we have to ensure that data surrounding our Support Services is used for limited, specifically stated purposes, accurate, kept for no longer than necessary and is kept safe and secure. It is important that our service users feel safe and that their data

is confidential and handled appropriately. For this reason we do not accept paper logging sheets or emailed word documents.

You will receive further information and guidance on the online logging sheet during training and if you have any further questions please contact a member of the Support Services Team.

### **Support and Taking Care of Yourself**

There may be times when you need support after a call – please do not ignore these feelings. The strength of our helpline service is that, at the end of the line, a caller will speak to someone who has experience of cervical cancer/cell changes. It is very natural that there may be times when a caller's experience may remind you of your own experiences and this may prompt an emotional response in you. Similarly, for those volunteers who are trained clinicians, we recognise that this brings its own set of challenges as you may not be able to guide a call the way you might in a clinical setting where the caller is your patient.

If you feel that you need to talk to someone, the Support Services Manager is your main source of support. You may call them during a shift, afterwards, or the next day. If they are not available, leave a message and they will phone you as soon as possible. A member of the Support Services Team will also ring you regularly to see how you are finding volunteering with us and whether there are any issues you wish to talk through.

You can also seek support from another helpline volunteer. Training together allows volunteers to build supportive relationships with one another – we strongly recommend and encourage this. It is also good to keep up the contact and to avoid isolation between training weekends with us. We also have a closed volunteer group on Facebook to help you keep in touch.

Please let us know if there are any personal circumstances that are likely to affect your helpline duties; whatever you tell us will be confidential. Be aware of your needs as well as potential callers. In this way you can look after yourself and know that you are giving your best to the caller. If you find that you need to take a short break from volunteering with the helpline due to family or work commitments, this is possible, you just need to discuss this with us. It is always better if we can plan for potential absence rather than a last minute cancellation.

We are constantly reviewing and developing our support systems so as to provide you with the best support we can. Please feel free to feedback at any time if there is something we could be doing better.

### **Taking Telephone Calls**

#### **Health and Safety**

You should arrange your environment for taking calls so that you are comfortable and do not cause yourself any undue strain. Think about your posture particularly your back. Do not support the receiver under your neck as this can cause neck and back injury. Keep any information you need for your shift within easy reach just in case you need it during the call. If you keep yourself safe and efficient, you won't need to interrupt the call. If you have to take the telephone into another room for privacy during the call, you should not have wires trailing freely where you or someone in your home could trip over them and become injured.

#### **The Optimum Environment for Taking Calls**

It is a requirement of Jo's Cervical Cancer Trust that you take your calls in private so the confidentiality policy is not breached. Quiet is also important so that your concentration, or

that of your caller's, is not affected by noise or interruptions. Disruption or lack of your attention can lead to the caller ringing off. It is essential that when you are on duty you should be the only person who answers the phone. Failure to follow these instructions could result in the caller feeling angry or upset and could affect the reputation and the work of the charity.

### **Helpline Answer phone Message**

The central helpline number is **0808 802 8000**. Callers phoning this number out of hours will hear a recorded message giving the times for the helpline that week.

If calls are received during your shift, calls will automatically be transferred to the volunteer/s on duty at that time assuming that the instructions for logging on have been followed. Please remember to log off at the end of your shift so that you or your family members do not receive calls from the helpline when you are unprepared for this.

### **Answering the Phone**

When the telephone rings, let it ring two or three times before answering. This will allow both you and the caller to focus and prepare for the call. This is very important for the caller who may have gathered all their courage to make this call. When you pick up the phone, you will hear the call being announced and notification that the call may be recorded for training purposes. At the end of the announcement say "Hello, (your name) speaking, how can I help" and then wait for the caller to respond.

### **Telephone Technology**

Jo's Cervical Cancer Trust uses specially designed telephone technology to run the helpline and volunteers will be given training and printed instructions on this after the annual training weekend.

It is preferable for volunteers to log onto the helpline via the internet. However, if your internet is not working or you are having problems logging on using your computer, it is possible to log on using your phone. It is important that when you are sent logging on details, you also have a printed copy somewhere in case you cannot access the electronic document.

### **Before Your Shift**

Ensure that you have all the information you need around you and that you will be comfortable while taking calls. It's a good idea to have a drink with you during your shift. Try to set things up for yourself a good ten minutes before the shift starts so that you do not have to rush things at the last minute. If you sound flustered and distracted when you take the first call, it is likely to unsettle the caller.

### **During Your Shift**

You are on duty for the whole shift. However, if you need to get a drink or go to the toilet then do so, since you should not be feeling uncomfortable and it will distract you from the caller and their needs. Simply click on the 'rest' button on the online system whilst you will be away from the phone and then click back to 'available' once you're ready to start taking calls again. It is really important that you follow this instruction otherwise you may not have time to get to the phone and the call will ring out which may give the caller the impression that the helpline is closed or unreliable.

Our call handling system allows a couple of minutes following each call before another caller can get through. This is known as the wrap up time and provides an opportunity for you to compose yourself and finish completing your logging sheet if you have not done so during

the call. If you need longer than the 'wrap up' time, you can temporarily log out of the system by putting yourself on 'rest'.

### **After Your Shift**

Once the shift is over, make sure you have completed a logging sheet for every single call you take. Inform the Support Services Officer of any technical issues or queries and if you had any incomplete calls (if caller hangs up upon answer). You will also need to inform us of any test calls you make to the helpline to check the line. Please note that we require you to fill in a logging sheet for ALL calls received, even wrong numbers or straight signposting.

### **Emotionally difficult calls**

Often new helpline volunteers express concern over how to handle a call where the caller is threatening to harm themselves, another person, or end their own life. Please be reassured that since the helpline launched in 2010, we have had only a couple of calls where a caller has used suicidal language. People generally call the helpline seeking information and support. However, we would like you to feel prepared in case this rare situation was to ever arise. If a caller discloses their intent to harm themselves, or another person, or to end their own life, please follow the instruction in the Suicidal Callers Guidance document.

*\*\* see our Suicidal Callers Guidance in section 2 of this manual.*

### **Abusive Callers**

The vast majority of callers to the helpline are simply looking for information, support and signposting. Since the launch of the helpline, we have only had a couple of instances where a volunteer has reported a caller as abusive. Very occasionally, a caller can feel angry about the situation they are in but we would not necessarily see this as abusive, merely an expression of their emotions. However, if a caller is being abusive please refer to the Abusive Call Policy.

*\*\* see our Abusive Call policy in section 2 of this manual.*

### **Boundaries: What We Can and Can't Do**

Boundaries are important to tell us how far we can go or what we can do – it may become difficult if we are not meeting the needs of the caller and therefore perhaps not our own. The very fact that you have volunteered to help and the caller wants more than you can offer can be difficult and stressful and leave you with a feeling of not accomplishing as much as perhaps you had hoped to.

By listening to and empathising with your caller, you have probably done more than anyone in relationship to their situation. Remember, you can't change their situation but you can help the caller to identify for themselves the next step they can take. Your best at the time of the call is good enough. Also, bear in mind that you are acting as the representative of the charity and the rules of the charity must prevail. This keeps you and the charity safe and avoids any reputational risk to the service and the charity as well as ensuring a consistent service is delivered to our callers.

So, for your own wellbeing, you need to recognise that you are there to listen, support, empathise, give information and, if possible, help empower the caller to make the best choices for them. You are not there to provide all the answers or solve their problems for them. If you do not learn to accept this, you may feel guilt, conflict and failure. However, it is quite normal for new recruits to the helpline to feel that they have not done enough. If you feel like this, talk to the Support Services Manager about it.

It is good to be a reflective worker and by discussing your calls constructively with either the Support Services Manager or your assigned member of the team, it will help you improve in areas you feel you need to. As your experience on the helpline broadens, you will find yourself gaining confidence and be able to recognise and accept the boundaries. In challenging situations when the caller may be pushing for you to 'tell them what they should do', it is perfectly right to remind the caller, gently, that you cannot, for instance, give them advice or tell them a particular treatment will cure them.

**It is our policy never to take contact details from callers for any reason other than to refer them to our Callback service.** This is to protect the caller, the helpline volunteer and the charity. Queries regarding information packs or support events should be signposted to the appropriate channels (either the office number or the website).

### **Callback Service**

The Callback Service provides callers with the opportunity to gain further information and support from the charity. You, as helpline volunteers, will offer your caller the chance to use this service and will then take their details accurately entering them into the online logging sheet. This information will then be accessed by our Support Services Advisor who will then contact them and arrange a time to carry out a further call. During this call, Support Services Advisor will seek to provide further information, continued support and also offer the caller the opportunity to give us feedback on their experience of the helpline which will help us to continue to improve the service.

*The Jo's Cervical Cancer Trust Helpline offers listening, support, information and signposting where appropriate. We never offer advice, particularly medical or legal advice. Sometimes there can be a fine line between offering support and advice. Your training helps you to understand and stick to the boundaries within which we operate but if you are ever in any doubt, speak to the Support Services Manager.*

### **Callback Service and Helpline Confidentiality Procedure**

Caller information is recorded only for the purpose of returning calls via the Callback Service. This information is kept on a secure electronic database. **Any handwritten notes with service user identifiable information must be immediately destroyed as soon as the information has been passed to the charity. If information is emailed to a member of the Support Services Team it must be immediately deleted from sent items folders in email accounts.**

Our telephone system does not reveal the caller's telephone number. Likewise, the helpline telephone number is withheld when the Callback Service returns calls. Please note that if an individual has chosen to bar anonymous or withheld numbers then we will not be able to return calls.

We do not pass on caller details outside of the charity.

Statistical information relating to calls is collected for managerial and supervisory purposes and may be shared widely. However, this data is collated anonymously.

#### *Exceptions when confidentiality may be broken*

- A caller is perceived as a serious and immediate risk to themselves by helpline staff or volunteers. This may include being actively suicidal or self-harming (please refer to the Suicidal Callers policy)
- A caller is perceived as presenting a serious and immediate risk to others.
- A call that seems to indicate abuse to children or vulnerable adults.
- A call which indicates possible terrorist action.

## **Information Giving On the Helpline**

### **Medical Information**

You will be provided with all the Jo's Cervical Cancer Trust publications at the back of this manual which you may quote and provide information from and we would also expect that you access the charity website for our extensive online information. You may also talk about your own treatment or procedure if it is relevant to the call but stress that this is your own experience and not a recommendation to follow the same route – just that it worked for you. It is interesting to note that most helpline volunteers who have been personally affected by cervical cancer or cell changes rarely share their experience with callers as they find it can detract from the caller's needs.

Remember, you are not qualified to give medical advice (even if you are a trained clinician in your working life) no matter how strongly a helpline caller appears to need it. This means you must never:

- Give a personal opinion or judgment about the treatment a person has had
- Give a personal opinion or judgment about a particular doctor or other practitioner
- Tell a caller what you think they should or should not do or what treatment they should or should not have.

When callers contact you, they are contacting Jo's Cervical Cancer Trust and you are acting as the charity's representative. Anything you say to a caller looking for information or support may be relayed back to a doctor or journalist or to someone else who may tell a doctor or journalist. Think about how what you say will sound when repeated to someone else and whether this could damage the reputation of the service or other areas of the charity's work.

If you are ever in any doubt about what you have said or not said after a call, contact a member of the Support Services Team for support. You should ensure you understand the charity's policy on treatments, contained in Section 2, and you may quote directly (and exactly) from that if you need to explain to a caller why you are not able to recommend any particular treatment.

### **Legal Information**

You are not qualified to give legal advice (even if you are a qualified solicitor in your working life), but there are plenty of people who are. If a caller wants advice on their rights, you should signpost them on to another organisation, like the Citizen's Advice Bureau or one of the specialist organisations or helplines listed in Section 6.

Jo's Cervical Cancer Trust cannot comment on or get involved in legal action that may be taken by callers or other service users. If a caller is pursuing that option, please do not tell them to write to the office. Staff there cannot help them and they will have wasted their time and money. It is also not acceptable to recommend a legal firm to them as we do not recommend commercial organisations offering services or products.

### **Personal Information**

Sometimes the caller may be interested in your experience with cervical cancer/cell changes. What is to be avoided is that it ends up as a conversation or comparison of symptoms and a sharing of the experience – this is not the role of the helpline. You may also find yourself being asked deeply personal or intimate questions that you are not comfortable to answer. It may be that the caller will want to know what treatments you have had and whether you are better – behind the question may be the need to know that you managed to get on with your life and that they will too.

The main feature of the helpline is that all the volunteers have had experience of the condition whether it is personally, professionally or through someone close to them. In this context your own experience is fundamental and valuable. You can be honest with them about how you are if you think that will be constructive. It is usually helpful to put your answers in general terms, such as “Many women are prescribed treatment A or B” or “In time most women find a way to manage their condition in the best way for them.”

This is an area in which you may need support. Some of this you will get through your training. If you have any other questions do ask the Support Services Manager.

### **Prognosis**

While this is partly a medical question, the implications for you on the helpline are much wider than that. The standard answer to a caller about her individual condition is that they should ask their doctor specific questions about their own case. It is important to remember that we are not here to patronise but to give clear information with integrity but at the same time being mindful that we don't cause further distress. Some questions may be hard to avoid but usually, when they are being asked, it's when the person is ready to hear the answer.

“Does anyone ever get better?” The caller may have been told that they need advanced treatment which some may take as meaning they are terminal and have little chance of survival. You must be careful that you resist the urge to just simply tell them “everything's going to be fine” as this will not help them. It is fine to discuss survival rates but, again, urge them to discuss their own particular case with their doctors. It is appropriate to say that cervical cancer is often treatable but is dependent on how extensively someone has it.

Similarly, you may have a call from someone who has been diagnosed as terminal and you will need to be careful not to give false hopes but explore ways in which they might improve their quality of life and direct them to helpful websites, organisations and local support groups that may help them to achieve this.

You may also receive a call from someone who is suffering from long term side effects from treatment and, again, it is appropriate to explore possible solutions and direct them to support groups and helpful websites.

It is important that we allow callers to express their fears and discuss the options for treatment and the importance of obtaining as much information about the options to make the best decision for them.

Encourage them to work with their partner/family if they have one as this can affect both parties and, at the same time, they can learn together and support each other. The important thing is that they find the best way to manage what they are going through and maximise their quality of life, whether they have just been diagnosed or are living with long term repercussions of cancer.

Jo's Cervical Cancer Trust always seeks to encourage communication between a caller and their healthcare professionals. We can have a positive impact on them feeling confident to ask the questions they need to in order to make good healthcare choices. Therefore, during a call, you should always encourage the caller to contact their clinician alongside other useful signposting.

For many callers, the first major step is for them to accept that they have cervical cancer/cell changes and move on to help themselves deal with it. If their call to you has helped them to do that, or set them on the path towards that, you will have accomplished a great deal.

## Signposting and Referral

There may be times when it is appropriate to signpost a caller to either another support service for Jo's Cervical Cancer Trust, or to another organisation.

You should not signpost a caller on to another service or external organisation just because you are finding the call difficult, unless it's because you do not have information on a specific topic and it is having a negative impact on the call.

Places to signpost a caller to;

- **The Jo's Cervical Cancer Trust Forum** – if the caller needs to feel less isolated and has access to the internet, the forum is a great place to meet others who may have gone through or are currently going through a similar experience.
- **Ask The Expert** – if the caller is asking a specific question about their condition or treatment which is not covered by the information provided or is very in-depth in a medical sense, you should advise the caller to submit the question via the Ask The Expert service on the Jo's Cervical Cancer Trust website. This way, they can access an answer from a trained medical professional. As a helpline volunteer, you should always encourage the caller to seek medical advice from their GP or consultant if they are concerned about any symptoms they may be having.
- **Support Events (Let's Meet, Mini Meet)** – if the caller wishes to talk more with others who have been affected by cervical cancer or find out more about how to manage the long term consequences of treatment, discuss where the next Support Event is and, if they would like to attend, you can either direct them to the website to fill in a registration form or direct them to the Support Services Team using the office telephone number. You must never take their personal details.
- **External Organisations** – if the caller needs information on a condition or situation outside of the information that we provide on cervical cancer and cervical abnormalities, signpost them to the relevant organisation within our list of useful organisations in Section 6.

We ask you to avoid recommending any consumer based product, service or company to callers to the helpline. This may lead them to use the product or service that you have recommended and they may find it unsatisfactory. This could then have a negative impact on the helpline and Jo's Cervical Cancer Trust.

## Training

*\*\* See Section 2 of this manual for our training policy*