

SUFFOLK RAPE CRISIS

SURVIVOR-FOCUSED CERVICAL SCREENING TOOLKIT

# TOOLKIT

Many people find being invited for and having their cervical screening (a smear test) uncomfortable and distressing. If you have experienced sexual violence, you may find it particularly difficult or traumatic. If you feel this way, you are not alone!

We spoke with survivors, and they shared that it can be a source of anxiety. Many have not attended cervical screening because of their experience of sexual violence. Some felt forced or pressured to disclose their experiences. Others worried the examination might trigger a whole host of distressing physical and emotional responses. These are all normal and reasonable responses.

However, cervical screening is an essential health check for our wellbeing and safety. And there is support available...

We at Suffolk Rape Crisis (SRC) have been working with specialist nurses and survivors to support you in understanding more about cervical screening. This has included identifying our rights, managing the practical concerns and taking care of the difficult feelings around cervical screening.

"We wanted to give something back, to support other survivors who might be going through some of the things we have gone through". Survivor

A group of ten survivors worked with SRC to create this 'Survivor-Focused Cervical Screening Toolkit'. Together, we have built a toolkit specific to the needs of survivors of sexual violence - to support all survivors with a cervix to manage their cervical screens. This toolkit is BY survivors and FOR survivors...

## BEFORE WE START, A NOTE ON ...

## **TERMINOLOGY**

#### SURVIVOR:

We use the term 'survivors' throughout but understand that this will not resonate with everyone.

#### **CERVICAL SCREEN:**

A cervical screen is to check the health of your cervix. It's not a test for cancer, it's a test to help prevent cancer. During the screening appointment, a small sample of cells will be taken from your cervix. Screening is for any person with a cervix aged 25 to 64.

## HUMAN PAPILLOMA VIRUS (HPV):

HPV is a group of viruses that are extremely common worldwide. Most types of HPV do not cause cervical cancer - usually, our immune system gets rid of it naturally and we don't even notice! For a small number of people, their immune system will not be able to get rid of HPV which causes the cells of the cervix to change (most cell changes will not develop into cervical cancer).

### **CERVIX:**

The cervix is the opening to your uterus from your vagina. It is located at the top of your vagina, just below the base of your uterus – it connects the two.

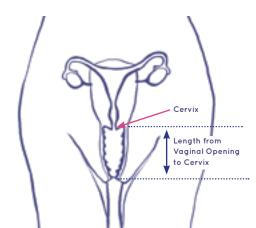
#### **TYPES OF CERVIXES:**

Your cervix is unique and no two are the same. You can have a low, high or average-height cervix, a straight or tilted cervix.

A low cervix means that your cervix sits lower in the vagina and a high cervix means that your cervix is higher in the vagina. Your cervix changes position related to the different phases of your menstrual cycle, as well as other hormonal changes.

It is also very common to have a tilted cervix – this mean that the cervix curves in a different direction, it might sound strange, but it's nothing to worry about.

There are lots of ways to make a cervical screening appointment better if you have a high or tilted cervix which we will talk about later in the toolkit.





#### **VAGINAL SPECULUM:**

A speculum is what nurses or doctors use to see inside your vagina. A vaginal speculum widens your vaginal walls so the nurses or doctor can examine your vagina and cervix. There is a spectrum of speculums – smaller to bigger, shorter to longer – ask the nurses to start small and go bigger if needed.

#### SWAB:

To collect a sample from your cervix, the nurse or doctor will use a swab (like a long cotton bud) or a soft brush. You can always ask to see one.

#### LUBRICANT:

A liquid or gel that you can apply to make the vulva or vagina area wetter. If you are struggling, the nurse can use a small amount of medical water-based lubricate (or water). For menopausal symptoms, a treatment course of local hormones or a vaginal moisturiser can be used.

#### **POSITIONS:**

Which position would you like to be in? You are in control!

You can lie on your back with knees bent up and feet together or apart.

You can lie on your left side with knees tucked up.

There may be stirrups, there may not be, but you can choose not to use them.







#### **CHAPERONE:**

A chaperone is an extra person in the room with you, if having another person is helpful to you. It can be a trusted person, a healthcare professional or a trained staff member (such as a receptionist). We will talk more about what their role is later in the toolkit.



# BEFORE THE APPOINTMENT... THE INVITATION

Getting the letter inviting you to a cervical screening can be upsetting and make you feel anxious. If you feel able to, talking about your feelings with someone you trust could be a first step to dealing with any issues or concerns the letter might be bringing up:

- You might want to talk to your partner, a friend or family member.
- You might want to talk to a doctor or nurse.
- If you are currently getting professional support to deal with your experiences of sexual violence, you might want to talk to your support worker.
- You could contact one of the support services at the end of this toolkit.
- If thinking about cervical screening is too much, you can tell doctor to take your name off the cervical screening automatic invitation list until you feel more able to cope with it. Please be aware that you may be asked why you want your name removed. The choice to disclose why is yours, you may simply want to tell the doctor that you do not feel comfortable with cervical screening at this time.

It is your choice whether to go for your cervical screening, and if you do go, you are in control of the appointment.

# APPOINTMENT

You can make some decisions about how YOU want the appointment to go, this will offer you some sense of control over your cervical screen.



Some of us may feel it is helpful to disclose that we have experienced sexual violence and how the procedure may affect us. There is absolutely no pressure to disclose anything for your appointment, but if you do decide that it could be useful to let the nurse or doctor know, this might help them better understand how to support you.



You can use one of these letters, both or neither to describe your situation and the extra support you may need to help give you a voice.



# APPOINTMENT

It is normal to find it difficult to attend a cervical screen. We may experience, or be worried about experiencing, strong bodily or emotional reactions.

When you experience a traumatic event your brain and bodies threat system is activated. The threat system is called the amygdala. The threat system is designed to keep us safe when we are faced with danger by making us...



FIGHT the threat



run away from the threat



FREEZE reduce harm from the threat



FLOP dissociating or disconnecting from reality

Some survivors describe being worried or anxious that this threat response will be activated during a cervical screening...

'I was concerned I would freeze'.

'I was anxious it would bring up memories and might trigger a flashback'. 'I was worried I would dissociate - sort of like I was out of my body looking down'.

'I was anxious I would feel panicky or have a panic attack'.

'I was concerned I would be overwhelmed by thoughts and feelings'.

This is normal. If your brain and body responds in this way it does so because it thinks it is keeping you safe. However, we are not in danger, and we need to reassure our brains and our bodies that the trauma is in the past and we are now safe.

## **SURVIVOR'S TOP TIPS**

But how do we know how our minds and bodies might react?

I use Body Mapping to think about my potential physical and emotional responses. Our bodies are wise, and I love taking some time to be curious and listen.

A Body Mapping activity (See Appendix Three).

How do we soothe these responses or reactions to make them more manageable?

I use Grounding. Grounding exercises are simple activities that bring my attention to the present moment and distract me by focusing outward on the external world. They help me feel less overwhelmed and more present, stable and safe.

## **GROUNDING...**

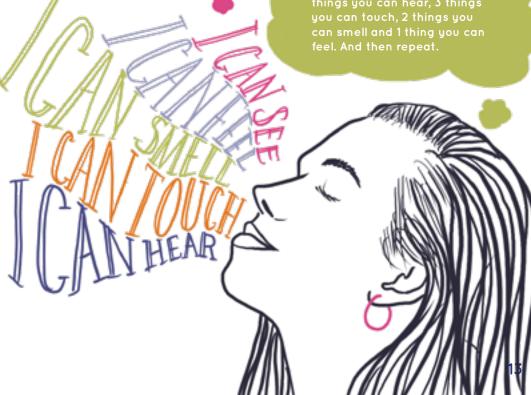
### Describe your Environment.

Describe objects, sounds, textures, colours, smells, shapes, numbers and temperature. Ask yourself: "where am I right now?", "what can I see?", "what is this room like?", "what colour are the walls?", "how many chairs are there in the room?", "what does the floor feel like? Is it warm or cold?", "what can I smell?"...



### The 5-4-3-2-1 Technique.

Take a deep breath and then list 5 things you can see, 4 things you can hear, 3 things you can touch, 2 things you







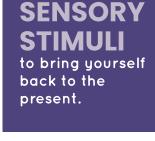
smelling essential

oils or perfume.

Suck a strong

mint or sour

sweet.



Use strong

Carefully **hold** an ice cube in the palm of your hand.



**Splash** cold water on your face.

Use a
Grounding
Object.

How do we make the process as comfortable as possible without telling ourselves to relax? I take three deep, slow breaths and, with each breath, sink my bottom muscles into the couch – quite naturally the vaginal muscles will follow on from this. It is a good way of ensuring a screening is as comfortable as possible.

What do we do if we don't want to be alone?

You are always entitled to a chaperone! I take someone I trust with me. They can be in the waiting room or the examination room with you to offer support. They may also be able to speak on your behalf about any worries you may have. If a trusted person isn't able to come to the appointment, you can request another member of staff to be with you for support (a healthcare professional or a trained staff member, such as a receptionist) - there will always be someone available!

Share our 'Advocacy Support Crib Sheet' with your chaperone to let them know their role, the ways you might react and how to support you (Appendix Four).

# AFTERCARE

The first and most important thing to say is well done! Whatever happened in your appointment, just getting through the door was a huge achievement. We hope that you can recognise the huge steps you have taken in your journey.

It is natural that after your cervical screen you may feel a range of emotions. Many of these feelings will ease by themselves over time.

But survivors have shared the ways in which they take care of themselves after their cervical screens...

## **25 WAYS**

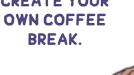
## TO TAKE CARE OF MYSELF



TAKE SOME TIME TO PAUSE.



**CREATE YOUR** BREAK.



**CONNECT WITH A TRUSTED** PERSON.



**CONNECT WITH** YOUR BODY TO **GROUND YOURSELF** IN THE MOMENT.







**TREAT** 



GO TO A SAFE PLACE IN YOUR MIND.











am strong



**LISTEN TO** A GUIDED RELAXATION.



CLOUDS.



TAKE SOME **BELLY** BREATHS.

THINK OF SOMETHING **YOU ARE GRATEFUL FOR.** 



**DO SOME GENTLE** MOVEMENT.



SLEEP.

HAVE A

WALK.

TAKE A **SHOWER** OR A BATH.

LET OUT A SIGH.





PUT YOUR TOES IN THE GRASS.

We have more of survivor's favourite self-care ideas, plus a video for caring, soothing and grounding ourselves after our cervical screen and a meditation audio 'Loving and accepting ourselves after our cervical screen'.

(Appendix Five).



# RESULTS

If all is clear, you will receive a letter, normally by post, within four weeks to inform you that your next screening will be in three years.

Sometimes results can be inconclusive, and you may need a follow-up. In this case, you will receive a letter, normally by post, within four weeks. You may be asked for a follow-up if...

- Sometimes the sample is inadequate (not enough cells taken or the cells cannot be seen properly under a microscope) in this case you will be asked to return in three months.
- If high risk HPV is found but no cell changes you will be asked to return in one year.
- If high risk HPV is found and cell changes are present, you will be asked to attend for a colposcopy appointment at the hospital.

Waiting for your cervical screening results may make you feel anxious. Whilst most people get a clear result, it is natural to be worried that something may be wrong. There are a number of specialist helplines and support services available if you need any additional support while you are waiting for your results.

## DIRECTORY

## SPECIALIST CERVICAL SCREENING HELPLINES AND SUPPORT SERVICES:

## Suffolk Rape Crisis Helpline 0800 0850 520 See website for further details https://srchelp.org.uk Rape Crisis England and Wales https://rapecrisis.org.uk/get-help/ #VeryImportantInvitation https://www.facebook.com/Cervical.Screening.Access/ Jo's Trust offer a specialist helpline: 0808 802 8000 https://www.jostrust.org.uk/ for support and information around any aspect of cervical screening, HPV and abnormal results. The My Body Back Project (https://mybodybackproject.com/) offers cervical screening, contraceptive care, STI testing and maternity care for people who've experienced sexual violence. At Your Cervix offers online peer support related to cervical screening. Find them on Twitter (@ At Your Cervix x) and Facebook (https://www.facebook.com/AtYourCervixx).

## **THANK YOU**

We wanted to take the time to say THANK YOU to all the survivors who have given their valuable time to share their thoughts, experience and expertise in developing the project. We really appreciate you being so open, honest and brave with your experiences and input, sharing them to create something truly transformative!

We also wanted to thank the Cervical Screening Nurses from**#VeryImportantInvitation** for their support throughout the project.

"This project has been especially close to my heart. I myself for years have not been able to attend a cervical screen due to fears around my own experiences of child sexual abuse and the uncertainties of practitioners and professionals having the right, informed understanding around common difficulties this community has with such a procedure. It's not only inspired me to truly consider attending a screen myself but has helped remind me that we are not alone, we have nothing to feel ashamed for, and there are people that truly do want to help us make wise decisions on behalf of our own health and bodies".

"I wanted to join this project as a chance to give something back to SRC and other survivors. SRC has helped me on my journey through trauma and into recovery, and I wanted to help enable other survivors to understand the importance of having their cervical screen, and having it carried out in the most sensitive and least intrusive way possible".

# TOOLS & RESOURCES



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#### **APPENDIX ONE**

## ADDITIONAL SUPPORT LETTER

Dear Practioner,

The person that is handing you this letter feels that they will need additional support during their appointment.

I may need extra support during my appointment as some things have affected my experience. The additional support I require during the appointment is as follows:

(Tick any boxes that you would like to request and add any other comments)
☐ I would prefer a Female/Male practitioner.
☐ I would prefer to have the appointment with a Doctor/Nurse/Either.
☐ I would like to be seen by Doctor/Nurseas I already
have a good relationship with them. I understand they might not be qualified
to do the test, and in this case, I would like to them to be present at the
appointment/talk to colleagues on my behalf.
☐ I would like to book a 'Pre-Appointment' phone call/in person just to talk
about cervical screening, find out more about what happens and discuss my
anxieties, needs and responses. I will not have the test at this appointment.
$\square$ I would like to see the clinical room before the appointment.
☐ I would like to request a longer or double appointment: Please state time:
This allows me a little extra breathing space before and after so I
can have the appointment at a pace that is more comfortable for me.
$\square$ I would like to request a speculum to "try out at home" before the
appointment.
$\hfill\square$ Please, talk me through the screen beforehand and/or show me the speculum
and/or swab.
$\square$ I would like to request the only person in the room is the nurse and myself.
$\square$ I will be bringing a someone I trust with me to the appointment as I am
anxious about being alone and want the extra emotional support.
$\square$ I would like to request a chaperone to be with me for support.
☐ I would like to have a fan in the room to keep it cool.

## **APPENDIX ONE CONTINUED**

<ul> <li>I would like to request space in the room for a breather after the appointment.</li> <li>Request a position: I will lie on my back with knees bent up and feet together or apart/I will lie on my left side with knees tucked up. +I would like a pillow.</li> <li>I would like to insert the speculum myself.</li> <li>□ Trigger words not to be used are</li> </ul>
(Tell them what words or phrases you prefer or are comfortable with, to help
them avoid any language that may be distressing, eg: do not say relax).
☐ Please do not stand
(tell them how heavy or light their touch should be).  ☐ Coping mechanisms, you can use include
(For example: I need you to tell me what you are doing/I need you not to tell me
what you are doing. I need constant communication/I need no communication).
☐ I have a high/titled cervix. The best way to collect a sample is
☐ If you cannot get a sample first time, please do not try again/please ask me if I
am happy for you to try again/other
Additional requests: Please state
If I hold up this Sign at any point, please pause or stop the examination.
You can check in with me by
Thank you,
Print Name:
Signature:

This letter is confidential. I understand you have to record this but only people directly involved in my care would have access to my records. I understand I can have my records audited and that the paper copy will be disposed of securely.

# PLEASE STOP!

Cut out of this toolkit so when making the appointment you can: read it out over the phone; email it; attach it to the online booking form; drop it off before the appointment; bring it along to your appointment; or share it in whatever way feels most comfortable to you.



Dear Practitioner,

I would also like to share that...

The person handing you this letter would like to disclose some things that may affect their experience in order to help you better understand how to help them during their appointment.

Some of the things listed on this page may affect my experience... (Tick any boxes that you would like to request and add any other comments)

I feel  ☐ Anxious. ☐ Fearful. ☐ Afraid it will hurt. ☐ Like a burden. ☐ Judged. ☐ Embarrassed.
How I might react during the appointment  I might cry.  I might not be able to answer your questions.  I might physically freeze.  I might dissociate.  I might get angry.  I might panic or have a panic attack.  I might have flashbacks.  I might shut down and withdraw – this might look like not being able to speak.  I might be shaking.  I might find it hard to process information, please can you write it down for me in might hear voices.
Additional reactions I might have:
Thank you,
Print Name:
Signature:

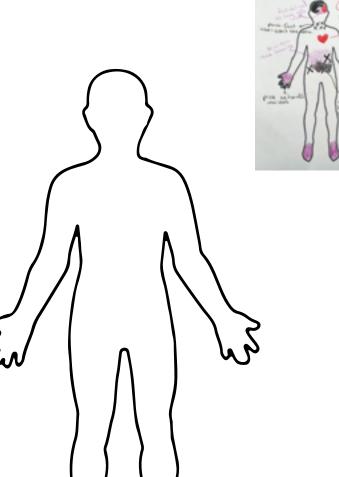
This letter is confidential. I understand you have to record this but only people directly involved in my care would have access to my records. I understand I can have my records audited and that the paper copy will be disposed of securely.

On the outline of the body, draw, colour, scribble, write where you might feel different sensations in the body. Think about what colour may represent these feels, whether they are still move, if they are hot or cold, open or closed... What might these sensations be telling you? This is unique to you but here is an example a survivor shared of her Body Mapping her responses and reactions to prepare for her appointment.

We invite you to try creating your own...

## APPENDIX THREE

## BODY MAPPING



## ADVOCACY SUPPORT CRIB SHEET

Dear Chaperone,
For my appointment, it would be helpful if you could
☐ Introduce yourself to me. ☐ Give me privacy to undress/dress. ☐ Give me an opportunity to ask questions. ☐ Offer me reassurance. ☐ Offer me emotional comfort. ☐ Distract me by talking about ☐ Stand
If I react this way
I need you to
If I react this way
I need you to
If I react this way
I need you to
(For example: If I freeze, I cannot respond to questions and I need you to stop the appointment. If I panic, I need you to distract me by talking about something completely different, eg: a film/TV show/food or I need you to ground me, this is my favourite grounding activity If I dissociate, my body will flop, and I need you to keep reassuring me that I am safe or hold my hand).
Thank you,
Print Name:
Signature:



## **MANAGING LOW MOOD:**

You may feel low in mood, even tearful, after your cervical screening appointment. This is normal, and it is okay to take some time out to pause, rest and restore.

- Take Some Time to Pause. Take some time-out for yourself. Maybe spend some time doing your favourite activity. Survivors suggested reading a book, swimming, knitting, or just doing nothing for a few moments whatever feels right for you.
- Rest. Take a moment to rest. We have been told that resting with your back on the floor and your legs against the wall can be really grounding and soothing.
- Create your own Coffee Break. Sit down with a cup of tea.
- Treat Yourself! You are inspirational! Take time to acknowledge that to yourself through a treat. Take yourself for a haircut. Wear those fancy earrings you would normally save for a special occasion. Cook yourself an indulgent meal or eat your favourite chocolate, just because. Make time for a long bath.
- Spend Time in Nature. Connecting with nature could be anything from going out into the garden; watching a sunrise or sunset; lying on the ground and wiggling your toes in the grass; or going for a walk outside.
- **Connect.** Connect with a person you trust from texting, calling to meeting a friend. Or maybe pet and cuddle your favourite furry creature.
- Listen to music. Whether it is in your headphones or blasting through your home, put on your favourite song or playlist – maybe it will even get you up and dancing.
- Journalling. Perhaps, try free flow writing a way of checking in with yourself and how you are feeling. There is only one rule to free flow writing do not stop writing! Even if you do not know what to say or want to stop, just keep writing. Start by writing the phrase "I am content when...". Set a timer (try one minute to start and if you enjoy it you can do it again increasing the time). From when the time starts to when it ends, do not stop writing. Write in whatever form it comes out. When the timer stops, stop writing. Put the pen down, you have done it! You can choose now to leave what you wrote on the page, or think about it some more, the choice is yours.

• Positive Affirmations. Affirmations are positive statements that can help you challenge and overcome negative thoughts. When we repeat them often, and believe in them, we can start to know them to be true about ourselves. We invite you to write down some positive affirmations for yourself. And then, if you feel comfortable, say them to yourself as often as you feel you can.

## **CONNECT WITH YOUR BODY:**

Connect with your body to ground yourself in the moment.

- Grounding Object. Choose a grounding object, perhaps a stone or a pebble. Hold object in your hand. Look at it really closely as though you have never seen it before. How many colours can you see? Is there anything you find interesting about your object? Notice how the object feels. Is it rough or smooth? Is it warm or cool? Does the temperature change as you hold it?
- Heel Drops. Begin by standing, and letting your eyes defocus, so you're not really looking at anything. Now, raise slowly up onto your toes, and then let yourself drop back down to your heels. Keep doing this at a slow rhythm, imagining that your entire weight drops down all at once through your heels. Let it make a loud thud! Bring your attention to the effect it has on your hips and lower back; maybe it feels as though the jolt loosens them. Try to let them relax. Do this for one minute.
- Shaking. Begin by standing and use your knees to create a gentle bouncing in your legs. Let your knees slightly bend, and then push backwards again into being straight, creating a soft shaking in your legs. Imagine this shaking can gently rock through your whole body, through your hips, up to your shoulders, and even your neck. Try to relax around your jaw, and your lower back and tail bone, as if the base of your spine is really heavy. Do this for one minute.
- Wave Breathing. Standing let your hands come to rest on the front of your thighs. Start noticing your breath. Now, as you inhale slowly, reach your chin forwards, glide your hips backwards, and lean your upper body forwards, creating an arch through your back. Pause for a moment, and then as you breathe out slowly, let your head relax downwards, bring your tailbone gently under and forwards, and round your back, coming gradually back into an upright position. Do this for around 8 breaths. This is a lovely way to extend and mobilize your spine. As you move, pay attention to the movement in your spine, and to how you feel your weight through your heels.
- Bamboo Swaying. Allow yourself to sway gently back and forth like bamboo in the wind for a minute. This rocking movement helps to discharge built-up

tension. You might also notice little tremors or shudders in your body, which might feel a bit unusual at first, but allow them to travel through you. It's a way that the body releases tension.

 Gentle Movement. Yoga for Caring, Soothing and Grounding Ourselves after our Cervical Screen by Lizzie Featherstone.



## **MINDFULNESS:**

We thought about mindfulness and how we would describe it. For us, mindfulness is about coming back to and experiencing the present moment in time at its fullest. This can involve appreciating all our senses, it can involve meditation, it might involve physical or mental exercises.

- Safe Place. Choose a place that feels safe, this could be a real or imaginary place. For example: mountain, beach, tree house, hot air balloon etc... Once a 'safe place' has been decided, sit in a relaxed position and just focus on that safe place and the feelings you would have go through the senses. Perhaps ask yourself... "what can I see?", "what can I smell?", "what can I hear?", if I touch things "what it feel like?". If your mind starts to wander, just gently bring it back, to the safe place and start to think again about what you can see, what you can feel, what is around you etc...
- Belly Breathing. Bring a hand to your forehead and the other hand to your upper chest. Your eyes can be open or closed depending on what feels most comfortable. Feel what goes on between the hands perhaps an energy flow or a change in temperature. When you are ready, keeping the lower hand on the chest, take the other hand to the belly and pause. Perhaps, couple this with counting inhaling for four and exhaling for four.
- Hug Yourself. Place your right hand under your left arm, perhaps in the armpit, and on the side of the heart. Then, cross your left arm, placing your left hand on your right shoulder. Take a moment to notice how this feels... This position can make you feel contained or settled, which may make you feel safe. Hold the hug and take a deep breath, filling your lungs and belly feeling them expand, and sigh out the breath. If you feel comfortable, repeat two more times. Place your hands in your lap and settle your breath for a few moments.
- Guided Meditation. Meditation for Loving and Accepting Ourselves after our Cervical Screen by Survivor Sam Huskings.












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