



RESOURCE PACK

WELCOME TO RETT UK'S VOLUNTEER DEVELOPMENT DAY

Thank you for coming and we hope you enjoy your day!

This pack should provide you with all the information you need for today and for your role beyond that.

You can also use it as a reference for the future.

Not everything in the pack will be covered in detail during the training, so please take time to read over the notes.



ABOUT YOUR ROLE



FAMILY CONTACT NETWORK SUPPORTER

About this role

Working with Rett UK as part of the Family Contact Network you will act as a point of contact for parents of children affected by Rett syndrome.

You will:

- Provide information about Rett UK and its services
- Offer emotional support
- Provide peer support
- Help with non-medical queries about Rett syndrome and related conditions
- Signpost to appropriate medical teams
- Maintain regular contact with Rett UK Family Support Manager
- Complete feedback form after each contact.

To be accepted for this role you must

- Be aged over 18
- Pass an enhanced DBS check
- Supply two satisfactory character references.

What we're looking for

- Parent or grandparent of a child born with Rett syndrome (for parent to parent contacts)
- A desire to help others affected by Rett syndrome
- Adaptable, flexible and willing to learn
- Friendly, confident and enthusiastic
- Ability to work independently and as part of a team
- Ability to represent others views and not just your own, even if these views are conflicting with your own
- Experience working with and supporting others (desirable)
- Empathetic and non-judgemental
- Excellent communication skills
- IT literate – able to use email and internet
- Ability to use social media (desirable)
- Ability to maintain confidentiality
- Ability to recognise boundaries and how and when to seek support
- Polite, courteous and reliable
- Commitment to attend initial and annual training.

We can offer you

- A unique and rewarding volunteer role
- Full training
- Great experience for your CV
- Regular support and supervision
- Reasonable out of pocket travel expenses as per our Expenses Policy.

Time requirements

We ask you to commit to checking your emails daily (for contact from Rett UK about a parent/carer needing support) and subsequently supporting a parent/carer as and when needed.

ABOUT YOUR ROLE



SUPPORT GROUP ORGANISERS

About this role

As a Rett UK Support Group Organiser you will be organising local meetings and events for families affected by Rett syndrome. Groups vary in size but all provide a meeting space for parents/carers and children/adults affected by Rett syndrome to socialise and access information and advice in a mutually supportive space.

You will:

- Be a friendly face and welcome parents and children/adults to the Group
- Co-ordinate meeting dates and attendance and liaise with the Rett UK Family Support Manager
- Be a point of contact between Rett UK, families affected by, and the Family Support Team
- Complete feedback forms with parents/carers/individuals
- Advertise meetings widely in liaison with your named Rett UK contact and/or communications team
- Have completed the initial training and committed to annual follow up training.

To be accepted for this role you must

- Be aged over 18
- Pass an enhanced DBS check
- Supply two satisfactory character references.

We're looking for someone who is

- Adaptable, flexible and willing to learn
- Friendly, confident and enthusiastic
- Ability to work independently and as part of a team
- Able to support others in a warm but professional manner
- Experienced working with and supporting others
- Empathetic and non-judgemental
- IT literate – able to use email and internet
- Able to maintain confidentiality
- Able to recognise boundaries and how and when to seek support
- Polite, courteous and reliable.

We can offer you

- A unique and rewarding volunteer role
- Full training
- Great experience for your CV
- Regular support and supervision
- Reasonable out of pocket travel expenses as per our Expenses Policy.

Time requirements

There is flexibility as to how often a group meets but ideally 3/4 times a year works well.

AIMS AND OUTCOMES



OVERALL AIM

To ensure that all Family Contact Network Volunteers and Support Group Organisers are up-to-date.

OUTCOMES

- Able to demonstrate knowledge and understanding of Rett UK processes for your role
- Demonstrate competence in engaging and supporting others
- Able to effectively communicate with those you are supporting.

WHAT WAS IT LIKE FOR ME?



- What were your feelings at key moments on your Rett syndrome journey or other key times in your life (diagnosis, operations, big life changes etc.)?
- Did you need any support at those times? What about the people around you? Is there a difference in the type of support you each needed?
- Looking back, is there a difference between what you felt you needed then, and what you think you needed?
- Could you have benefited from Rett UK's services at the time?

FEEDBACK FROM PEOPLE WE HAVE SUPPORTED



- 75% of those attending a Support Group said that they agreed or strongly agreed that as a result of attending the Group they felt part of an informal Support Group
- I found it very hard to deal with my daughter's diagnosis until I met Hayley at the Support Group
- It is encouraging to know that there is a great support network out there who are willing to share their experiences. This can be more comforting than 'medical' support as it seems more real life
- It's great to know this service exists. Rett UK were so quick to get back to me after I made contact and so quick to match me with a Family Contact Network Supporter. I am very grateful
- It was helpful to me to talk to a parent who had a child who also had a Rett syndrome. It was nice just to run through a few things and get some feedback about how things work now, compared to when we got our daughter's diagnosis
- It was extremely helpful!
- Katie emailed me a few weeks ago but I've only just replied. I'm sure you'll understand, life takes over sometimes!
- Yes I feel Michelle provided great information
- We had a chance to speak to Lorraine and it was fantastic. She was very helpful and so friendly, we did feel more reassured after speaking to her. Thank you so much for making this possible.

STAGES OF SUPPORT



WHAT ARE THE KEY THINGS TO THINK ABOUT DOING AT EACH OF THESE STAGES?

1. Beginning a supporting relationship

- Being introduced
- Getting to know each other
- Being clear about what you can and can't offer
- Beginning to feel at ease with each other
- Negotiating when/where you meet or call and for how long
- Knowing what to expect of yourself, the other person and the Family Support Manager.

2. Getting to know the person

- Encouraging dialogue
- Exploring the issues
- Listening and validating
- Spending time getting to know each other.

3. Focusing on the issues

- Drawing out the issues from their 'story'
- Being clear about what you can support or help them with
- Identifying areas of potential support and encouragement.

4. Helping the person develop new perspectives

- Helping make sense of their 'story'
- Agreeing what you can do that will help
- Broadening their view of the issues and not going for a 'quick fix'
- Developing your own objective understanding of the person and the issues
- Creating alternative scenarios for their life.

5. Standing alongside

- Encouraging and affirming
- Evaluating
- Being prepared for not achieving as planned
- Celebrating achievements.

6. Ending the relationship

- Identifying that the other person has no more need of support
- Both begin planning for an ending
- Leaving a door open for the future.

PARENT TO PARENT SUPPORT – THE REFERRAL PROCESS



Contact received

Contact is received into the Rett UK office by phone on **01582 798 911** or to Rett UK the email address, **support@rettuk.org**



Rett UK staff will be in touch

Rett UK Family Support Team will be in touch with the parent/carer to gather any information needed to match them to the right contact or signpost to a more appropriate service.



Make a match

A member of the Family Support Team will give you a call or drop you an email to check your availability and confirm that they've matched you.



Send information

We will share your profile with the parent/carer and also send you any relevant background information we have about the parent/carer so that you know a little bit about them before you are in touch.



You make contact with the parent/carer

Please make sure to contact them within 48 hours by their preferred method of communication and keep notes of your conversations (let them know you're doing this!). Keep in touch with Rett UK and let us know how it's going by completing the feedback form.



The Family Support Team get in touch with you

Your Rett UK point of contact in the Family Support Team will be in touch after two weeks to ask how things are going.



How did it go?

The Rett UK Family Support Team will be in touch to see how things went and to ask you and the parent/carer you have supported to complete a feedback form.

SUPPORT GROUP ORGANISERS ROLE



Induction will cover:

- Finding a venue
- Venue checklist to include:
 - Risk assessment
 - Access requirements
 - Accident prevention
 - Accident log
- Photo and Video Consent form
- Data protection and confidentiality
- Social media
- Differing needs
- Liaising with the Rett UK Family Support Team
- Promotion
- Peer support.

A FRAMEWORK FOR YOUR ROLE AS A FAMILY CONTACT NETWORK SUPPORTER OR SUPPORT GROUP ORGANISER



- A parent to parent relationship is a helping relationship
- It isn't a friendship or a romantic relationship
- You're there for the person, not for yourself
- You can talk about your own experiences if it is for their good, not for your own good!
- You must maintain confidentiality
- Ideally, you shouldn't give your mentee your phone number or any other personal contact details
- From experience, we have found this can blur boundaries. If you both want to remain in contact after the peer support relationship has ended that is fine. You can then share your contact details outside of Rett UK
- Rett UK will support you if you do not wish to remain in contact after peer support has ended
- The role description allows you to be flexible in a way that feels comfortable for you. For example, it would be fine to speak more or less frequently according to need and most importantly if you felt comfortable with this.

**The Golden Rule is: only do what you feel comfortable with.
If you have any doubts, discuss them with the Family Support Team.**

CONFIDENTIALITY



- Information learned through parent to parent support is treated as confidential to Rett UK and not to the individual receiving it. It will only be shared within Rett UK with those who need to know it to function effectively and offer the best possible services to people affected by Rett syndrome and their families/carers
- As a parent to parent supporter, you can and should share information with the Family Support Team who support you, so that you can do your role effectively with the support from the office
- Generally, personal information cannot be disclosed outside Rett UK without the person's consent. Where they have given their consent, a written record should be kept of this if possible. Sharing information with other agencies, with consent, can be a helpful way of ensuring that people are effectively supported. As a parent to parent supporter you might often be encouraging people to make contact themselves, rather than contacting agencies on their behalf
- Withhold your number by pressing 141 from a landline or change your settings on a mobile so that 'show my caller ID' is switched off
- Personal information can only be disclosed outside of Rett UK without consent (i.e. breaking confidentiality) when there is a perceived risk of harm to the person in question, or to another person. This is often called a Safeguarding concern and sometimes a court order may be issued to disclose it
- Unless it is a dire emergency, which is highly unlikely, you will never make the decision to break confidentiality yourself, but will discuss the situation with the Family Support Team and be guided by them.

RISK MANAGEMENT & SAFEGUARDING



We give parents/carers who ask for support, clear information explaining our Confidentiality and Risk Management Policies.

It says that all discussions between them and a volunteer are confidential within Rett UK, **except** when the volunteer is concerned about the safety or welfare of the person or the people around them (especially children/vulnerable adults).

Concerns could be for:

- People at possible risk of **abuse** (harm from others). Abuse could be **physical, psychological, sexual, financial, or neglect**
- People at possible risk of **harm from themselves through suicide, self-harm or self-neglect.**

Try to be open with the person you are supporting, about your concerns, and your duty as a Rett UK volunteer. Encourage them, where possible, to take steps to gain help themselves. But **always** inform the Family Support Team of your concerns.

The Safeguarding Team in Rett UK will discuss and evaluate the situation with you. They will decide on the course of action and support you through the next steps.

Keep in touch with the person as appropriate. Try to keep the relationship going within reasonable boundaries.

But **remember your limits**. You can't solve this person's problems for them. You are not responsible for another person's decisions or actions. The Safeguarding Team can offer on-going support when appropriate.

Always look after yourself and use support and supervision. The Family Support Team and the Safeguarding Team will support you and provide de-briefing. It can be emotional and stressful supporting someone.

PARENT TO PARENT SUPPORTERS – THE SAFEGUARDING REFERRAL PROCESS



What do you say if you RECOGNISE, suspect or are told (disclosure) about abuse?

- Explain to the person your duties with regard to confidentiality – that you CANNOT promise to keep a secret, that you have to share information with your line manager, but not other colleagues
- Explain that investigations will be done sensitively, and that it won't be you that does it
- Reassure the person that they will be supported and protected
- Tell the person what you are going to do next.

What do you do if you discover, suspect or are told (disclosure) about abuse?

- Reassure the person using the service
- Make sure they are safe – including making sure they are not about to go back to an abusive situation
- REPORT to Rett UK's Designated Safeguarding Officer, Social Services or the Police WITHOUT DELAY
- Preserve any forensic evidence
- Arrange any necessary emergency medical care.

If you discover, suspect or are told (disclosure) about abuse, please do not:

- Show shock or disbelief, or be judgemental
- Ask leading questions or press for more details
- Promise not to tell anyone
- Promise that it won't happen again
- Contaminate, touch or remove any evidence
- Confront or contact the alleged abuser if you suspect this may increase the risk of harm
- Give information to anyone other than a designated person.

What do you RECORD if you are witness to, suspect or are told that abuse is occurring?

Write it down! Include in your statement:

- The FACTS – which are much more important than opinion
- What was said, and by whom, as word perfect as possible
- Use a body map if required
- Any witnesses
- Date it and sign it
- Pass it on to Rett UK's Safeguarding Officers within 24 hours.

THE PROCESS IN DETAIL



You recognise a concern

You may recognise, suspect or are told (disclosure) about abuse.



Find out more

Find out more detail if you feel confident that it won't put the person at further risk of harm and if you feel comfortable asking.



Record

Record your concerns as soon as possible so that you don't forget the detail.



Report

Report your concerns using the Incident Report form and forward it to Rett UK's designated Safeguarding Officers within 24 hours. Make sure to record as much detail as possible and accurately record anything the person said about the abuse, in their own words (not yours).

Situations like this are very rare, but it's important to know what to do.

Remember that the Family Support Team are always there to support and help you.

LOOKING AFTER YOURSELF



As a Family Contact Network Supporter or Support Group Organiser, you are a very important person to the people you support and to Rett UK, and that means you need to take care of yourself with our support when you need it.

You are responsible for recognising if you are not able to continue in your role, because of things happening in your personal life. Equally, when things change and the role is no longer for you, you need to let us know.

Please inform the Family Support Team at Rett UK as soon as possible. A one-line email is enough. We have had a situation where a volunteer simply stopped contacting someone in their Family Contact Network Supporter role and, as a result, the person was very hurt and disappointed.

It is completely OK to take a break if you need it but please keep us informed.

Looking after yourself includes:



Recognising when your own stress levels are increasing



Not taking on too much



Sticking to boundaries



Recognising when you feel out of your depth



Asking for help from the Rett UK Family Support Team



Keeping an eye on your own feelings and talking about them with the Rett UK Family Support Team or with or with friends/family (but don't break confidentiality).

RESOURCES FOR VOLUNTEERS



All the information and resources you will need in your role within the Rett UK parent to parent support network will be provided by the Family Support Team.

This includes the following:

- Support Group Organisers Handbook
- Rett UK useful/relevant contact details
- Expenses Policy and form
- Policies and procedures to help you in your role
 - Safeguarding Children, Young People and Vulnerable Adults Policy
 - Safeguarding Young People and Vulnerable Adults Enquiry form
 - Social Media Policy
 - Data Protection Policy and Confidentiality and Information Sharing Policy
 - Equality and Diversity Policy
 - Complaints Procedure Policy.



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