

# React Supporter Manual

Produced by The REACT team

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# Contents

## 1) Introduction Page

## 2) What is a REACT Supporter? Page

- Motivations and limitations

## 3) What to Expect: the job Page

- Site Content and information access
- Example posts and example scenarios
- Day to day tasks
- Signposting and support
- Working online
- Monitoring risk and safeguarding
- Timeliness
- Language
- The role of hope and empowerment
- Creating resources
- Supervision

## 4) Support and Training Page

- Confidentiality
- Managing risk and clinical issues
- Supervision
- The importance of self-care
- Managing stress, anxiety and repeatedly reading challenging scenarios

## 5) Things to remember - Top tips Page

## 6) Appendix Page Appendix I: REACT Toolkit Risk protocol example page

- Appendix II: REACT Toolkit Inappropriate Posting Policy
- Appendix III: *What can I do when things really go wrong?* Blog co-authored by Sue Flowers and Val Minns
- Appendix IV: Safeguarding - PREVENT Counter Terrorism Strategy
- Appendix V: Supervision agreement and protocol? (Awaiting Bill / Steve)

- Appendix VI: REACT Module Summaries
- Appendix VII: Example posts and example scenarios
- Appendix VII: Example Risk Email

## **1) Introduction**

REACT is the Relatives Education And Coping Toolkit, an online self-help package or toolkit for relatives and friends of people with mental health problems associated with psychosis or bipolar. It has been put together by a team of people with expertise in this area, including clinicians, researchers and relatives of people with psychosis or bipolar.

In order to support the successful delivery of this healthcare intervention a team of REACT Supporters (RSs) are employed to support the users of the site in a number of ways:

- To access current information pertinent to their own specific contexts
- To signpost them to useful resources
- To provide further support by managing and monitoring online forums and direct messaging systems and writing blogs to provide additional information on carer related topics. These messaging systems and blogs are an important and bespoke part of the intervention where RSs can draw upon their personal experience of supporting others in an informed, supported and professional manner.

## **2) What is a REACT Supporter?**

The REACT Supporter (RS) is a new role that utilises the lived experience of people who support their friends or relatives who have on-going mental health conditions such as bipolar, or psychosis.

A RS can be an adult of any age, gender or ethnicity but should have experience of helping someone close to them manage these conditions. They should be caring and prepared to use their own experience constructively as a means to supporting others through a potentially distressing caring role.

A RS will need to have good I.T. skills, writing ability and linguistic competency; strong research, problem-solving and creative, solution-focussed thinking skills are also essential attributes. They should be resilient, have an openness to learn, undertake training, utilise supervision effectively and an ability to function well within a team context. They should have commitment and energy and where possible a good understanding of carers' rights and support systems.

It is recognised that care for a relative or friend is not a simple all or nothing thing but more of a continuum or process where caring responsibilities will fluctuate over time. If a potential RS is overwhelmed by their own current caring responsibilities then this role might not be for them at this time. However, the nature of the role, means that they will sit within a team able to offer understanding, support and guidance when personal caring situations fluctuate. Deciding whether this is the right time for an individual to become a RS will depend on assessing how it fits with individual personal situations and the support systems offered by the team.

### **Being a REACT Supporter: Motivations and Limitations**

A key motivation for RSs to undertake this work may be the desire to help other relatives; the difference an RS can make has a significant impact on managing the stresses of the job.

REACT participants said

“Finding REACT has been like finding an oasis in the desert... I can’t describe how good it has been to be able to discuss issues around relationships, and starting a family with others who are or have been in a similar situation. “

“The forum has made me feel less alone. I really wish that REACT had been around a few years ago when our lives were first turned upside down by the diagnosis of psychosis and the crisis that led to that diagnosis.”

“To be able to voice my feelings, and to get replies from people who had or were experiencing the same made my life a lot easier.”

Whilst training and support will be given to the post-holders it is important to remember that they are an important part of a team of experts, and they should feel valued as such; they are not expected to work in isolation and will not be expected to have all the answers to complex and often distressing situations. Expertise is validated by having lived through a personal set of experiences, others in the team will bring their own informed perspectives to provide the best possible response in an atmosphere of mutual respect.

It is important to remember that working on the delivery of a specific health intervention such as REACT will have constraints. This may be challenging for some people who may be motivated to undertake this type of work through a desire to transform and fix problems. Whilst REACT has the potential to improve the lives of many carers it cannot, on its own, transform every problem in mental health care. It is therefore important to remember that this is not possible within the remit of the

job. REACT is NOT a crisis service and a RS cannot fix everyone else's problems. A RS can, however, provide independent support and information and make other people's lives much more bearable. The use of personal narrative and storytelling, and the provision of hope within this context are crucial.

### **3) What to Expect: the job**

REACT Supporters are relatives of people with bipolar and psychosis; they bring their own lived experience of how to deal with the challenging situations that arise as a result of supporting someone with complex mental health needs. They are employed to help other relatives to use the REACT toolkit site, direct them to resources and signpost them to other methods of support. The RS's can also get information from other people in the team if they need to – this may include psychologists, psychiatrists, mental health nurses, social workers as well as other RSs.

In addition to supporting others through their use of the online site it is likely an RS will also be part of the implementation of the REACT toolkit within new contexts, assisting in the promotion of the service and building links with carer groups and across relevant networks. It is important that confidentiality and story-sharing issues are considered before this public facing work commences.

On the REACT toolkit site the RSs can give information, but they cannot and should not give advice on what someone else should do. This is because the RS will not have the detailed contextual information about the situation, or relevant professional training and responsibility. They may want to signpost to a range of options that could be available to a relative, but they must always make it explicit that individuals should only make decisions that are right for them and that they do not endorse any specific courses of action. The use of blogs within the Toolkit can be a useful way of citing more direct ways of approaching certain situations i.e. '*What can I do when things really go wrong?*' blog in Appendix III

**In this section you will find the following further information:**

- Site Content and information access

- Example posts and example scenarios
- Day to day tasks
- Signposting and support
- Working online
- Monitoring risk and safeguarding
- Timeliness
- Language
- The role of hope and empowerment
- Creating resources

RSs may want to draw on their personal experiences to illustrate examples and points, but their main purposes are to work online to signpost and support others, monitor the site for risk, provide information, empathy and empowerment in a sensitive, accessible and timely manner.

An RS will be part of a team that also promotes services, researches and develops new resources for the site such as blogs and newsletters.

## Site content and information access

There are **THREE** parts to the website that an RS will need to be familiar with and have access to:

- The **REACT toolkit** - the main website interface that relatives and friends use, where they can post forum messages and send direct messages to an RS. *Username and password protected.*
- The **dashboard** - this is the 'backstage' of the website where the RS can search and select posts quickly, and used for adding blogs etc.
- The **secure part of the site** where the information is stored that might need to be accessed if there are risk issues for a participant. *Username and password protected.*

In addition to these **three interfaces** the RS will need to monitor and access:

- The REACT Supporter email – this is where notifications about messages on the site arrive
- Drive folders where administration documents are stored – the RS will have their own arrangements as to where documents are; making sure everyone knows where key documents are is an important part of the job.

The **REACT toolkit** - the main website interface contains:

#### **REACT Modules**

#### **The REACT Group Forum**

#### **The REACT Direct Messaging System**

#### **The REACT Modules**

There are 12 modules in the toolkit all coproduced by a team of expert relatives, clinicians and academics based on the best available current evidence.

Although the information is about people with psychosis or bipolar disorder in general, the toolkit is designed to help relatives to make this information specific to their family or friends by identifying key questions they may need to ask to get the information they require. Case examples and videos are used extensively to aid illustration. The content of the toolkit reflects the key ingredients in current evidence-based family interventions. Useful summaries of the content of each module can be found in Appendix VI REACT Module Summaries

#### **The REACT Group Forum**



The REACT Group area is a place for relatives and friends to share their experiences and gain peer support. First a note on the terms used:

- A forum is like a category e.g. 'Questions about medication'.
- Topics are conversations within that category e.g. 'What is an anti-psychotic?'.
- Replies are posts (something someone has written) within any one topic.
- The series of posts under a topic are also known as a thread.

Only REACT Supporters can start a new forum, but all users can start a new topic within an existing forum.

**The REACT Group forum should be checked on a regular (at least daily) basis.**

People may use the forum regularly, or infrequently. There may be people who initiate topics, those who respond to posts and there may be people who just read the posts that are on the site without actively posting themselves.

Participants may give a short overview of their own story and their current situation. Topics may come up such as news stories which have concerned or interested people; some may be seeking reassurance, simply wanting to voice their worries or receive peer feedback.

Supporters should try to interact

- if there is a need
- if it looks like others are not responding or there has been a time lag
- to refocus, redirect and add valid support or information

There are three key tasks on the forum:

1. To respond to direct queries or comments from relatives. Supporters should try to respond as quickly as possible to any posts to ensure relatives feel there is someone there to help them.

2. To generate activity. If the forum is quiet then REACT Supporters can add new posts to existing forums or create new forums to stimulate activity. Supporters should try to respond as quickly as possible to any posts to keep conversations alive. The more activity that there is on a forum, the more people will join in. A key strategy to generate activity is to ask open questions that invite people to give their opinion on something.

3. To 'hide' any inappropriate posts so they are no longer visible to users. The forum should allow expression of a range of views, but posts that are inappropriate can be hidden by the REACT Supporter. Relatives can flag posts they consider inappropriate and the REACT Supporter should then check these and decide if it requires hiding.

See Appendix II: *REACT Toolkit Inappropriate Posting Policy*

### **The REACT Direct Messaging System**

Quite often direct messages will tell a story; the participant is often at a critical point and usually appears to be seeking advice. RSs can give factual information and support but cannot provide advice; they must respond to all direct messages from site users except where they are clearly ending the conversation.

Much of what is written above about forum posts applies to direct messages however the queries on the direct messages may be more specific or unusual. Responses must show that an RS has read and understood the message, for example by reflecting back what a person has described.

REACT Supporters cannot give advice but can help a person think through the possibilities available to them. Using open-ended questions can be helpful. Sign-posting and retrieving useful links and information is also helpful. These things can help them clarify what it is that is on their mind, reassure them and redirect. The Supporter may need to ask for more information from the person in order to give them a better reply.

Some of the most difficult messages are when there isn't a specific piece of information needed. Rather, a person may be very upset, sad or frustrated and in a situation which is just plain distressing. Although it may not be possible to change these situations, an RS can play a vital role by offering a listening ear and giving good quality information.

## Example posts and example scenarios

It is helpful if an RS can retain an open mind as to how they approach and respond to posts on the REACT site. There is no one way to respond to any one post – each RS responds in their own style with their own unique insight and experiences. They should draw attention to resources within the toolkit and be mindful that they may not want to over burden someone with too much information within any one post. This requires RSs to be very familiar with the content of the modules in the toolkit. RSs should also be mindful that they can signpost a relative or friend to the private Direct Messaging system, should a message become of a particularly personal nature: however, they should respect the decision of that person should they want to post in an open manner on the public Forum in order to receive a wider range of responses from others. An exception to this would be in the case of inappropriate posting and where a scenario was felt to be too distressing or offensive for others; in this case the post would be removed from public view and discussed at Supervision. A decision might be made to remove a post permanently, or to put it back up. In either case, the relatives would be encouraged to continue the conversation through the direct messaging service to ensure they are still able to access the support they need.

In order to demonstrate the range and versatility of writing styles and approaches we include in **Appendix VII** two example scenarios with four different posts written by experienced REACT Supporters.

## Day to day tasks

**An overview of day-to-day tasks of a RS is listed in this section.**

There are two main ways that relatives will interact on the site – the REACT Group Forum and the Supporter Direct Message page; an RS will receive email notifications when someone sends a Direct Message or posts on an existing Forum.

- It is important to check the RS email and action as needed, an RS will need to be able to triage the emails and use a management system to ensure nothing is missed.
- Be aware that as a relative or carer, a participant's experience of services may be different from what an RS expects. Assumptions should not be made about what might be in place. The role is to support the participant whatever services are used. Supervision can be a useful place to discuss such problems, utilising the team to identify how best to tackle issues of access to healthcare support.
- An RS will be working alongside other supporters, so it is therefore useful to develop a category system such as can be found in a Microsoft Outlook email box *mailbox* that demonstrates who is dealing with an email/notification and when it has been completed. Red flags can be used to show something is in progress or in need of review.
- The contents of messages should be checked and prioritised. Some might not need a response, or perhaps just a quick '*Glad to hear that*' or '*Thanks for sharing*' type message.
- There may be some general administration or IT issues that have a simple quick fix or need passing on to other RSs. There should be clear information about who is responsible for IT supported and RSs should be informed of how to contact them directly.
- An RS needs to monitor all messages from participants and respond to them as needed; there will be an email notification of new direct messages.
- An RS needs to check the REACT Forum at regular intervals during the day; responding to posts or stimulating conversation if needed. There should be an email notification of new forum posts.
- RSs need to check if any posts have been reported as inappropriate by site

users (by going to the dashboard part of the site) and where necessary, removing posts from public view.

- RSs can add new forums (categories of discussion) to the site as needed. Each Forum has its own topic threads, which any user can create, but only a REACT Supporter can create a forum so this should be done with care.
- RSs should work with their team to write and plan updates to the REACT blog as necessary.
- RSs must monitor, identify and respond to risks at all times.
- RSs should respond to participant support needs, i.e. responding to participant messages with empathy and understanding whilst imparting information but NOT advice, signposting to information in the modules, the resource directory or from other reputable sources, such as NICE guidelines or Trust websites where necessary.
- An RS should always read the content of posts and messages carefully. Site users are likely to be distressed and sometimes it can be unclear what they are saying. Asking open-ended questions can be a useful way of assessing a difficult situation, i.e. 'can you tell me how you are feeling right now?' 'Can you describe the support you are currently getting from health services' Be sure to only read what is there and not to make assumptions about a person's situation.
- If an RS is particularly worried about a scenario that has been described, asking someone if they feel safe can be a useful way of clarifying risk.
- Ensuring that links and resources listed on the site are the most up to date, relevant and still functioning is also an important part of the RS role, especially when posts on the site may be fewer.

## Signposting and Support

Relatives should be **signposted** to useful information on the toolkit, in the resource directory or occasionally (with team guidance) to trusted and reliable websites: With time and continued communication this is likely to empower and enable individuals

to take bespoke actions to improve their individual situations, personal wellbeing and the journeys of their loved ones.

Relatives should be **supported**; by being given empathy and understanding to individual contexts and situations, remember, support can come in many shapes and sizes; some people might simply just want to be heard and their experiences and situations understood as a form of validation, others may want specific information that might be hard to track down.

An RS may feel they need to just put an event to one side for a while if they find a scenario difficult to respond to. In cases without an identified risk, allowing time for reflection and consideration can be more important than responding quickly. Also, within a team, there may be occasions when another RS is better placed to provide a particular response. It's important to ask for support and advice from the other RSs and the supervisor if it's required.

## Working online

It is important to note that working online is very different from meeting with someone face-to-face or even having a telephone conversation. A relative or friend can post messages at any time of the week, day or night, whilst an RS will normally only be working during office hours. Becoming accustomed to working in this way can take some time; an RS may not hear from someone after they have posted a timely response to a message showing high distress; sometimes the RS may not hear for days or even weeks. Remembering that REACT is not a crisis service, and discussing posts within the team can help an RS understand that they have done their best and hopefully mitigate any possible anxiety. Residual anxiety resulting from posts should always be discussed openly either in team meetings and/ or supervision.

It is also important for an RS not to 'backfill' messages and imagine what else might be going on for an individual, but instead to respond to the message as it stands. For an RS it is often not possible to access an immediate response; nonetheless, utilising

open questions can be a helpful form of relieving an RS's anxiety about a situation and finding out more. For example, asking a direct and specific question such as 'Do you feel safe?' whilst not an open ended question, can be important to ask and can very much help assess risk.

IT Support and System Failures: it is important to understand the REACT IT support systems to ensure that the system functions effectively and remains online. Having a clear IT failure sheet with key contact details for IT support is recommended. Having such a document easily to hand is of help should a participant report that the website is unavailable, the login page fails, registration process fails or for any other significant IT challenge.

## Monitoring Risk and Safeguarding

Monitoring the site for risks and inappropriate posts is an important part of an RSs role, although it should be noted that all site users are also provided with guidance about this. In all aspects of checking the site, RSs must identify risks to participants; these risks may be to the participant or another person and for this reason every post on the Forum and Direct Message systems should be read in depth, and in the majority of cases, responded to in a timely manner.

When a risk is identified it is vital to the safety and security of everyone that the Risk protocol is strictly followed (*an example of this can be found in Appendix I*).

Deciding upon what is appropriate for a group forum can also be a challenge, so drawing on the wider input from the whole team can be helpful.

It is important to remember that for most people using REACT, they will be in some form of distress; therefore it is vitally important that RSs are clear about their role in assessing for risks whilst on the site. RSs will be given specific training in how to do this, and will attend regular supervision sessions where risk issues can be discussed (*see the Supervisors Manual for further information about this*).

Assessing for risk is as much an art as a science and where situations are complex a conversation with a team member and clinical supervisor is recommended; where

even a potential risk to self or another is possible then review by a clinical supervisor is crucial. Assessing risk in a rigorous manner is important for the safety of the relative and ensures that the anxiety for dealing with risk is mitigated: as with most jobs, over time and with experience identifying risk should become easier.

When reviewing posts for evidence of risk it is useful to consider whether anything written in the post indicates that the person writing the post is in danger of harm (either to self or by others) and/ or whether anyone else involved is similarly at risk. (this is especially important to note when children are mentioned, in which case safeguarding policies should be strictly adhered to).

The tipping point for distress becoming something more serious is not always clear and an RSs reaction to a particular sense of change or 'gut' reaction to a post should be taken seriously until further advice and clinical input is sought. As a rule of thumb, an RS should adopt the policy of *'If in doubt, check it out'*, therefore having a team around an RS who are always available to advise on identifying and responding to risks is important.

It is important to note that having a clear risk protocol in place is essential should a high-risk scenario occur, however the likelihood of this in reality may actually be relatively low, given that either no or very few instances of risk were reported as HIGH during the research period of REACT.

Risks can be broadly categorised and responded to as follows:

**Distress** – and RS should expect site users to be distressed but sometimes participants can show a level of distress that is concerning. Where a relative is showing extreme distress, an RS should follow the risk protocol to send a standard email (written for site users in extreme distress) that points them to other forms of support such as their GP, The Samaritans, Crisis Services etc.

**Physical harm** – there may be concern that a site user or other person may be at risk of physical harm



**Adult or Child Safeguarding** – an RS may be concerned that a child or vulnerable adult or child is at risk of harm, neglect or abuse.

**Immediate risk of serious injury or death** – if there is a imminent high risk, such as severe injury or death, the appropriate emergency services should be contacted. The site user's name and address can be accessed through the dashboard system.

All NHS employees have a responsibility to safeguard and protect vulnerable adults, young people and children from abuse and maltreatment. For the purposes of REACT, this responsibility will be to recognise and report any safeguarding concerns that arise through online interaction with site users. A RS can use the NHS Trust and Local Authority Safeguarding Team to get advice on safeguarding risks (make sure you have the contact details of your local team.)

Any safeguarding concerns must be reported to Local Authority's Safeguarding Team (for adults) or Children's Social Care Team; the relevant local authority (i.e. where participant lives). Each NHS trust will have information on how to report a safeguarding concern on their website; the site user's name and address can be accessed through the dashboard system. Phone calls to report concerns must be followed up in writing via whichever secure method is prescribed by the relevant authority

Safeguarding adults, young people and children now explicitly includes the duty to prevent radicalisation of vulnerable people into violent extremism. (Please see PREVENT information below)

You do not have a duty to investigate risks of abuse but you do have a duty to

- Recognise
- Respond
- Record and
- Refer

See Appendix IV for information on PREVENT a part of the UK Government's Counter-Terrorism strategy. This aspect of risk was also not applied at any point

during the research study as the need did not arise.

### **Information Sharing**

Information about site users will not be shared outside the team unless necessary and proportionate to the risk identified. When thinking about sharing information, the risk of not sharing information must also be taken into account. Essentially personal information is only shared when the risk identified specifically requires it.

### **Responding to risks: Logging information**

All risks must be logged on the REACT system, indicating:

- What level of risk has been found – Low/ Medium/High (see Appendix I)
- Where the risk was identified –Forum/ Direct Message/ Email/Other,
- Who identified it – which RS found it,

What action was undertaken – Standardised risk email sent/ Bespoke email sent/ Services contacted etc. See appendix VIII: Example Risk Email for further information. It is really important as a RS to be familiar with this protocol and how the online system works.

- What follow up actions were taken – when follow up supervision was undertaken and by whom including the name of the Clinical Supervisor.

Following a period of managing a risk of any category, RSs should seek supervision; they should also allow themselves some cool down time. Reviewing actions and ‘cooling down’ after a highly stressful event is an important action for any team member to undertake, however workloads and differing cultures might present barriers to this.

It is vitally important to the health and wellbeing of a RS that there is adequate time at work to process and adjust to the complexity of risk scenarios. Unlike other team members they will not have had clinical training and are unlikely to have seen a range of similar experiences. More importantly a risk event is not likely to be processed quietly at home, especially as a RS may have some form of caring responsibility that they will be returning to after work. Checking-in with personalised self-care strategies is an important resource for RSs to draw on at this time.

Managers should be aware that risk scenarios might trigger difficult memories, heighten a sense of responsibility for others and wanting to help or invoke feelings of 'what if' panic i.e. what if this happened to the RS's own friend or relative?

## Timeliness

The amount and frequency of direct posts and forum messages can vary widely from day to day. Ideally all posts are responded to in a timely and appropriate manner and not left unanswered where a request for further information or support is made. Even if the RS doesn't know the answer to a specific question, responding with a promise to look into it and get back ensures the participant knows their message is being dealt with.

When there are a significant amount of posts at any one given time this can cause a heightened sense of anxiety for an RS. If this occurs, triggering an overwhelming sense of responsibility, it is important to remember that REACT is not a crisis service and that the whole team has a role to play here.

With multiple posts, in the first instance it should be possible to read all of them, look for risks, and subsequently respond to those needing the most urgent attention. However it can be quite a complex decision process to prioritise any one set of problems over another, and if this occurs the RS should respond as best they can, then raise at supervision the increase in quantity or 'bottlenecking' of posts if this seems to be an issue. The use of the skills of the team of RSs can also be useful in these situations, where it may sometimes be possible to hold over a reply (if it is not urgent) and where a response may fit better with the skill set of another team member.

## Language

The use of language on the site is important. Supporters should be aware that they have no idea when a relative might have time to go back online and see what

response has been posted. It is OK to spend time composing posts, re-visiting and re-editing to ensure that responses are accurate and specific.

When wanting to signpost someone to a resource but not give advice it can be useful to ask purposeful questions i.e. *'Have you thought about approaching your local council Adult Social Services team?'* OR *'Your local council Adult Social Services team should be able to provide you with further information on this point'* RATHER THAN *'You need to go to your local council Adult Social Services team for that'*.

The aim is always to ensure that the participant feels their message has been read and understood. For some people it is the very act of feeling heard and listened to that starts the healing process for them. Such experience can be a powerful healing tool, personal stories and empathy can further develop a real sense of validation for an individual relative in a challenging situation. The linguistic use and narrative of an RS can reduce a sense of isolation and in some cases provide hope for others.

## The role of hope and empowerment

Supporting a sense of hope can be a powerful tool to help others. RSs should sensitively and actively seek out such information by sharing their own experiences of what provides them with hope and by encouraging others to post their own stories by open-ended questions on the forum about this.

The approaches described above of sharing resources and information can also empower others; it is important to share resources, including site resources which relatives may often not have seen, in an enabling manner and to foster a sense of autonomy and independence for others.

It is important that both RSs (and the participants they support) realise that intensive individual support is neither feasible nor appropriate within this role. RSs need to understand that there are real limitations of what they can offer within the very functional role of delivering support at scale to a large number of people who potentially might have nowhere else to turn to.

During the research phase of REACT, RSs created poems and guidance points to assist them in their work (as featured below). These were placed in the office environment as daily visual reminders of key components of the job, and, where relevant, were posted in threads of communication such as on The Power of Words forum.

### **The Power of Hope**

If I had a superpower it would be to spread some hope  
To give our world a super boost and help us all to cope.

If I had a superpower it would be to nourish true insight  
The gift to see the light within ourselves that shines so truly bright.

If I had a superpower it would gladly share it with you all  
I would spread some love like fairy-dust and make our troubles small.

If I had a superpower it wouldn't be to make things right  
But to help all those who struggle to 'not give up their fight'.

**By REACT Supporter, Alison Jean Hankinson 2018**

### **A Rule of Thumb**

REACT Supporters...

Have you applied **Common Sense**?

Have you written with **Care** and **Courage**?

Are your words **Neutral** and **Impartial**?

Have you made it clear you [are not giving Advice](#)?

Have you explored all the options you can find  
and presented them in a balanced way?

**Have you given some HOPE today?**

## Creating Resources

RSs should be constantly researching new resources in response to issues presented on the site and those raised by their wider team. It is important that this research is consistent with REACT goals and that new information is agreed at a team level – nonetheless being able to respond to overview issues creatively is a significant part of the job.

For example, if several people using the site have posted concerns about an inability to deal with their anxiety effectively, then a RS should have the ability to work with the wider team and author a blog with useful links and resources which can be made available to all toolkit participants. During this process it is important to take cross-team input and advice, utilising supervision to ensure new information is based on best evidence and quality resources.

New information, web links and resources can also be used to further improve the resource directory. Ensuring that links and resources listed on the site are the most up to date, relevant and still available is also a useful required activity for an RS to undertake when posts on the site may be lesser in number.

## 4) Support and Training

It is vitally important that an appropriate, person-centred supportive working structure is designed around RS workers and that a period of training and induction is undertaken before a RS commences working on the live REACT site.

In addition to an organisation's generic HR and employment training requirements, bespoke/ specific training should be offered around confidentiality, managing risk and clinical issues and the importance of self-care.

## Confidentiality

Confidentiality is tripartite and should include:

- The RS
- The RS's friend or relative
- Friends and relatives using the site

Third Party confidentiality issues are complex and an RS's relationship with story sharing may well change and evolve over time. Adequate supported time to consider the implications of sharing narratives is a vital training requirement of the post.

**Remember, your story belongs to your relative or friend  
as well as you**

*Passwords: it is really important that login details for REACT are never shared with anyone else and that Supporters logout after every session.*

RSs should consider carefully whether they want to take on an anonymous pseudonym on the site, and should be given guidance on appropriate use of language to protect the identity of their own loved ones. For example, in order to bolster personal confidentiality an RS may prefer to refer to an experience with their loved one as with 'my relative' rather than 'my son, daughter, partner etc.' thereby protecting the confidentiality of their relative or friend's personal situation. Changing the gender of a friend or relative can also be considered, to protect anonymity of a third party; but it is advisable to explore this in some detail during supervision and seek further advice and training.

*NB The role of personal narrative in peer support work training delivered by the Institute for Mental Health at Nottingham*

*<https://www.institutemh.org.uk/education/peer-and-welfare-support> has been recommended as a useful training tool by an RS during the research period of REACT and on-going supported reflection in supervision has also proved invaluable.*

## Managing risk and clinical issues

Repeated exposure to unpleasant stories and challenging experiences, over time, can have a negative impact on any individual. This may be particularly pertinent to an RS, who may well be in a challenging situation of their own at home, so appropriate support and regular supervision is especially important to maintain their health and wellbeing.

The employing organisation has a duty of care to consider the impact of the job upon the individual and how these can be mitigated as part of current Health and Safety Law. <http://www.hse.gov.uk/pubns/lawleaflet.pdf>

RSs also have a responsibility to understand in advance what the role requires, and to consider carefully whether this is a role that they feel they want to take on at a particular point in time.

The role of a supervisor is explained in more detail in the Supervisors Manual but in essence this is to provide qualified clinical support to reflect on key areas of the supporter role including clinical issues raised on forum or personal messages, risk issues, changes needed to improve the site and RS wellbeing.

During an RS's induction process (and within regular supervision) training and support will be given in identifying risk; the process of supervision is also useful to reflect on possible risk situations, enabling a dynamic process across the team for reflection on complex scenarios.

RSs are responsible for ensuring that inappropriate language or behaviour is not used on the site. If an RS notices something that might cause significant distress to participants or adversely affect others then they may remove the post and seek further advice from a Clinical Supervisor or Risk Manager.

In either of these scenarios there should be a clear protocol which should be followed rigorously – see Appendix I for an example of a risk protocol and appendix II for an inappropriate posting policy. Further information about risks and clinical



issues can be found later in this manual in - What to Expect: the job - Monitor the site for risks and inappropriate posts.

## Supervision

Supervision is a vital part of the training and support package needed to undertake the RS role successfully. The role of a supervisor is explained in more detail in the Supervisors Manual but in essence this is to provide qualified clinical support for such key areas as clinical issues raised on forum or personal messages, risk issues, changes needed to improve the site and RS wellbeing.

Ideally, a RS should have access to both group and individual supervision. Within group supervision it is important to utilise the varied skill set of the team to reflect on complex scenarios and gain wider perspectives, whereas individual supervision can be a confidential space for more person-centred reflection with clear structure and guidance from an experienced supervisor. It is important that the aims, purpose and confidentiality limits of supervision are agreed and clarified between a RS and their Supervisor at their first meeting. A supervisor may work hard to develop a sense of trust and support with an RS, ensuring that an RS feels not only listened to, but also understood. Feeling really heard by a supervisor is as important as an RS feeling comfortable about raising difficult and important issues that might be of an intensely personal nature to them. A supervisor will not know about an issue that has not been raised with them, therefore developing trust and a good working relationship is an important part of a successful supervision. The mutuality and interdependence of supervisory work – i.e. both sides working with goodwill to produce a desired outcome - can be the key to the successful delivery of REACT. See attached Appendix V: Supervision agreement and protocol (tbc)

## The importance of self-care

The RS will find that a lot of time is spent working on the Forum and Direct message systems, and giving others permission actively to look after their own wellbeing. People in a caring role often put others' needs before their own and with the

additional online REACT supporter role it is vitally important that the supporters develop strategies to look after themselves.

Understanding how to be pro-active about self-care is something that doesn't need to be done in isolation, and ideally should be at the heart of working practice.

Therefore, in addition to planning for wellbeing with the supervisor, the team as a whole can also work together to share best practice ideas for self-care. The 5 ways to wellbeing - **Connecting, Being active, Taking notice, Giving** and **Learning**, are good markers for RSs to check in with personally, whilst also sharing their learning with others on the REACT toolkit site. See

<https://www.gov.uk/government/publications/five-ways-to-mental-wellbeing> for further information.

Ideally a RS should develop a personalised wellbeing plan, as a unique response to their wellbeing needs.

Some key protective factors that RSs have previously drawn upon that can assist with this are:

**Perspective** (using reflection and prioritisation to decide what is important)

**Mutual support** (being there for one another, recognising the need for humour and venting)

**Individual choices** (knowing what works for you- exercise, socialising, hobbies, families, chocolate) and

**User care** (giving, knowing you are having a positive impact on someone else's life)

Other simple techniques may also be of use, such as:

- Group activities, i.e. walks and conversations
- A wellbeing hour\* if an RS is feeling particularly stretched (\* although the feasibility of this would need discussing and approving with the line manager in advance.
- Getting out of an office environment during the lunch hour,
- Going for a walk,
- Not working late,
- Managers ensuring an RS is not being asked to attend meetings or have conversations that run over /outside working hours

These are all useful ways of RSs preserving energy and looking after themselves.

For an RS to spend some time thinking about what gives them pleasure and hope can be a useful starter to this work. An RS might ask themselves if they could take a daily, weekly and monthly wellbeing pill what would it look like?

For example:

Daily – might be a 10-minute stroll outside, or drinking a delicious cup of coffee (when all anxieties are put aside for a few moments and they can concentrate on something else, i.e. the flavour and experience) or...

Weekly – an RS might want to attend an arts or sports class that makes them feel good or...

Monthly – it might be a day out with a really good friend or...

We are all different, so our wellbeing plans should look different; it's useful to spend some time before you start work thinking about some simple strategies and working out what might work for you.

Understanding your own wellbeing needs and those of others working with you on this can be critical in developing self-awareness, thereby enabling you to manage stress and anxiety in a more effective way.

If an RS is able to feel valued as part of the team, for their own unique insights and skills, has opportunities to connect with others, to overcome challenges collectively, to access professional development and to strengthen their resilience through being authentically themselves, then they are more likely to thrive within this role. Being authentic in this role is not just about drawing upon personal experiences in an open hearted and honest manner; but also having the voice and courage to speak up when the role becomes challenging or when issues from home are affecting you.

## Managing stress, anxiety and repeatedly reading challenging scenarios

Whilst some of the many of the stress factors facing RSs do wax and wane, over time they may remain significant; it is therefore important that supporters develop the ability to adapt and cope within the working environment. A supervisor should be able to offer support to an RS in helping them to ensure a balance within their work roles and in working with them to create a positive environment within teams; this will support everybody's mental and physical wellbeing.

Repeatedly reading, and re-reading difficult posts, which may have detailed descriptions of sometimes very painful, or even horrific events can become distressing for an RS. Whilst this might not be on a daily or even weekly basis it is important that RSs are well- prepared and are able to voice their concerns and anxieties openly within the confidential and supportive environment of supervision.

Developing strategies within the team to protect a RS's wellbeing such as holding regular discussions in supervision in anticipation of the stress of work and its potential impact on an RS, rather than afterwards, can be a useful tool in ensuring RSs remain well and resilient. Some key themes for both a RS and Supervisor to consider around the development of resilience strategies are around a RS's **Awareness, Balance and Connection** in the world.

Maintaining a sense of balance can be a key component in preserving a sense of identity and overall wellbeing. An individual who is able to undertake the supportive role of an RS is likely to have already achieved some element of balance, nonetheless it is important that assistance is given when needed to ensure an RS can preserve their personal resilience and balance by achieving and maintaining a healthy balance of work, rest, play and socialisation with friends and family. This is not an insignificant feat when an RS is most likely to have real and on-going caring commitments to others who are managing challenging mental health conditions of their own.

Developing deeper self-awareness can also be a useful survival tool, where journal writing, emotional support from team members or personal counselling can be introduced into the processes of self-care and support where relevant.

A wider connection with the world, through social activities with colleagues or group workshop or training activities in the arts and sports can further assist an individual's personal tolerance levels and may assist an RS to reconnect with and process difficult emotions; the relevance and need for these should be assessed on a case-by-case basis with each RS working on REACT.

It is important to note that by the active participation of an RS on the REACT site, potential negative impacts can be mitigated to some extent through meaningful and creatively responsive work. Utilising difficult experiences to create new meaning through the development of creative writing, poetry, music and artwork (all of which can all be used as resources for the site) can be an important part of creating new meaning, challenging negative beliefs and feeling part of a new community of resilient REACT relatives.

## **5) Things to remember - Top tips for a REACT Supporter**

Always keep important Risk, Safeguarding and IT contacts to hand – and make sure you have memorised passwords

**REACT is NOT a crisis service** and you cannot fix everyone else's problems; you can however provide support and make other people's lives more bearable

**Feeling responsible** - notice when and if you start to feel too responsible for others

**Cool down** – if you have had to deal with especially stressful scenarios, especially when they involve serious risk incidents, make sure that you make time to cool down and process your experiences

**Your own story belongs to your relative as well as you:** spend time thinking about and discussing confidentiality within the team the impact of your (shared) story on your friend or relative

**Speak Up** – it is not always apparent when things are going **wrong** for you at home: don't assume because others know you have a close friend or relative at home with a mental health condition that they will understand how you are feeling; if things within your work trigger difficult or emotional responses for you tell someone, remember you are not (and do not need to be) invincible to be a REACT Supporter

**Look after yourself** – take a break, speak to others, remember as a RS you need to look after yourself as well as those around you

**You can learn current best practice** information to apply to your relative, family or friend so enjoy absorbing the information on your own recovery journey!

**And remember that you are doing a really important job** that is helping a lot of people!!

## **6) Appendix**

### **Appendix contents**

Appendix I: REACT Toolkit Risk protocol example page

Appendix II: REACT Toolkit Inappropriate Posting Policy

Appendix III: *What can I do when things really go wrong?* Blog co-authored by Sue Flowers and Val Minns

Appendix IV: Safeguarding - PREVENT Counter Terrorism Strategy

Appendix V: a) General supervision principles

b) Example supervision contracts

Appendix VI: REACT Module Summaries

Appendix VII: Example posts and example scenarios

Appendix VII: Example Risk Email