Action on Postpartum Psychosis

Media Pack
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Thank you very much for expressing an interest in becoming a Media Volunteer for Action on Postpartum Psychosis (APP).

APP is often contacted by journalists from women’s magazines, national newspapers, TV and radio asking for human interest stories about families affected by Postpartum Psychosis. Engaging with the media can be a good way of raising awareness about Postpartum Psychosis and getting information out to health professionals and the general public. However, deciding to talk openly about PP requires careful consideration.

This pack outlines the issues that APP members feel it is important to consider before telling your story to journalists. It outlines our media policy, goals and key messages, and the support that APP can provide to women and partners when considering talking to the press.

We hope that it will help you to make a decision about whether being a Media Volunteer is right for you. If you have questions about being a Media Volunteer, please get in touch at media@app-network.org or telephone the APP office on 020 3322 9900.

Why do we need Media Volunteers?

• Myths and misunderstandings about Postpartum Psychosis exist in the media, and contribute to a poor general public and health professional awareness of PP.

• Newly diagnosed women and their partners search for information on the Internet and often only find stories about tragedies that have occurred. We would like to tackle stigma and redress this balance by providing stories about the real issues women and their families face, and include stories of hope and recovery.

• There is frequently confusion about what PP is, and the differences between PP and Postnatal Depression. We aim to get accurate information into the public domain about PP - its symptoms, outcomes, causes and care.

• The poor public awareness of PP directly impacts upon illness outcomes for women. Delayed identification of symptoms by first line health professionals, family and friends result in longer, more severe, and more difficult to treat episodes. This delay increases the risk of tragedies occurring.

• Poor awareness in communities impacts upon the recovery process, adding to women’s feelings of isolation, alienation, shame and guilt following an episode of PP.

• The knowledge and commitment to create change that arises from the lived experience of PP has a power to engage and influence people in a way that facts and figures from experts cannot.

• Volunteers have the best knowledge of their local area and can advise us on local issues and stories of interest (for example the closure of a Mother & Baby Unit, a local fundraising event, etc), which could prompt a story.
APP media policy

What we would like to achieve

Media workshop participants identified the following aims, goals, and policies to guide APP’s media engagement strategy:

**Aims**

- To enhance public awareness and understanding of Postpartum Psychosis.
- To address stigma and misinformation in media representations of Postpartum Psychosis.
- To support families affected by Postpartum Psychosis by: improving their ability to seek help; improving access to information; and decreasing the isolation felt by those who have experienced Postpartum Psychosis.
- To provide advice and support to individuals affected by Postpartum Psychosis when going public with their stories.

**Goals**

- To address stigma – PP can happen to anyone.
- To tell people what PP is (and what it’s not).
- To tell people that women can recover and what helped with recovery.
- To explain what help is available.
- To talk about early symptoms to aid recognition.
- To explain severe symptoms.
- To explain that, with the right care, you can have another baby.
- To campaign for Mother & Baby Units and high quality services in all regions.
- To break down myths about the impact of PP on bonding, and on children as they grow up.
- To explain the difference between PP and Postnatal Depression.

**Volunteer Training and Personal Contact**

APP has a responsibility to ensure that all of our Media Volunteers are: 1) currently in good mental health; 2) have had time to think about their own story; 3) have considered the risks and benefits of going public and made an informed decision; 4) have sufficient support and information when taking part in media interviews; and 5) are thoroughly briefed about the key messages we hope to deliver through media opportunities. The process for Media Volunteers (see page 10) will reflect these responsibilities.

**The Volunteering Process**

1. Media Volunteers will express their interest in being on the Media Panel via web-form, email or telephone.
2. A Media Information Pack will be sent out by email or post.
3. The Volunteer will be contacted directly by Lucy Vernall, APP Trustee and Media Coordinator, to discuss further.
4. The Volunteer and Lucy Vernall will work closely to create a Case Study for the APP Media Panel database.
5. When opportunities arise, Lucy Vernall will contact the Volunteer and organise communication with the journalist. Lucy will liaise with both parties throughout the process.
Types of News Outlets

Print media: APP will aim to work primarily with broadsheet newspapers and reputable monthly magazines. We will use caution with tabloid newspapers, but recognise that the reach of such publications is vital in our aim to raise public awareness. Requests from weekly magazines that contain stories designed to shock will be refused. News agencies will be viewed with extreme caution, given the lack of control over where the piece is accepted, but decisions will be taken after a discussion with the individual journalist.

Broadcast media: APP wishes to support Volunteers making contact with their local radio stations, particularly when there are issues of local importance. APP will also focus on BBC Radio 4 (particularly Woman's Hour) and television documentaries or drama storylines featuring Postpartum Psychosis. APP is unlikely to support any documentary makers wishing to film a person at high risk of PP through pregnancy, as we believe this could exacerbate the illness.

Individual relationships: APP will aim to develop and sustain relationships with individual journalists who are supportive of our aims. A database of journalist contacts will be compiled and notes kept where the interaction has been both positive and negative. Lucy will ensure regular contact with supportive journalists and will send invitations to appropriate events.

Own pieces: APP will support Volunteers who would like to write their own stories and articles, TV or radio pieces, and we will proactively look for professionals to produce these pieces.

Media Campaign strategy

Lucy Vernall will work closely with the APP Board of Trustees and wider APP members to set themes and objectives for targeted media campaigns. These may focus on raising public awareness, targeting specific groups, presenting research findings or addressing national issues such as Mother & Baby Unit provision. We will aim for this to generate print, broadcast and social media coverage, and reach set objectives (e.g. after a certain number of months, a percentage of the population will have heard of Postpartum Psychosis). Changes in website, peer support forum, membership and Facebook traffic will be reviewed.

We will aim for one Campaign per year. Campaigns must reflect the current resource capabilities of APP, and be designed and funded to ensure that the outcomes of any publicity can be managed.

Networking & Dissemination

APP will develop and maintain links with media officers in other charities and organisations (including MIND, the Big Lottery, Royal College of Psychiatrists, Bipolar UK, the University of Birmingham, Cardiff University, the Time to Change Media Advice service, the Science Media Centre and more). We will aim to ensure that they are aware of our specialist expertise and knowledge of Postpartum Psychosis.

In some cases, we may ask our Media Volunteers whether they are happy for their details to be shared with partner charities, such as MIND, if working on joint campaigns.

We will disseminate both local and national stories via social media (APP Facebook page and Twitter @ActionOnPP).

Copies of all interviews and print articles will be kept by APP and, where appropriate, linked to the Media section of our website.

Policy to be reviewed annually:
date of next review – 1st May 2014
Issues to consider before engaging with the media

Engaging with the media can be a really positive way of sharing your story to make a difference to others. However, it is important to consider both the benefits and potential risks of ‘going public’ with your story.

Looking after yourself

- It is important to make sure that you feel well enough to tell your story. It is often tempting quite soon after recovery to want to share what you have been through.
- Seeing your story in print, or the portrayal of your experiences on TV or radio after editing can be a mixed experience.
- Spending time with a journalist and talking about such a difficult time in your life can be very draining, and you might want to make sure you have the right support in place.
- Think carefully about the risks you could be exposing yourself to by going public.
- Are you comfortable with your family, friends, colleagues & your local community reading about your experience?
- Will it cause you unnecessary stress?
- Give yourself some time to think about how much detail you want to share.

Privacy and anonymity

- Before speaking to a journalist it’s a good idea to consider whether you are happy for people to be able to identify you personally from your interview. When thinking about your privacy, here are some things to consider:
- Do you want to remain anonymous? Journalists do not like their interviewees to give false names – but the decision is yours.
- Do you want to use your first name only? Make sure APP knows your preference, and if you are in contact with a journalist using your real email address, make sure you have their agreement to use your first name only.
- Are you happy to have your photo printed with an article? How do you feel about including photos of your child/children?
- It is important to know that once your story is public, it’s public. If you do a piece for a local paper, other newspapers, including nationals, could pick the story up and run it without needing to inform you.
- Could people look you up on Twitter or Facebook? – check your privacy settings.
- It’s worth thinking about the photos of yourself and your children that are on social media sites and consider removing them temporarily. Unscrupulous outlets might look for photos here to illustrate their piece.
- If you have an unusual name, you might want to describe your location generally e.g. ‘Yorkshire’ or ‘North East’ so that, should anyone wish to, they cannot identify your address or telephone number from the telephone book or electoral register.
- Make sure you don’t name the health professionals involved in your care personally, to protect their privacy as well as yours.

Looking into the future

- In the Internet age, stories are increasingly accessible and can be accessed for much longer than they once were.
- This means that before going public, you need to consider not just your current situation, but try to consider your future one too. Do you mind future employers or colleagues reading the article? How would you feel about your children accessing the article as they grow up? What about parents at your child’s future school?
- How might your family feel about this information being available in the long term?
Types of media

- You should consider the kinds of media you are happy to do.
- There are pros and cons of each, for example, radio allows more anonymity than a TV interview. Print media could be less stressful as participants do not have to ‘perform under pressure’. TV interviews have the benefit that it is your own words and body language that reach the viewer, so there is less opportunity for journalists or editors to misunderstand or misrepresent.

Your control over the content

- How will you feel if aspects of the story are not told as you would like?
- Some journalists will let you review a piece before it goes out. Some will allow you to edit or comment on the piece, or review it for factual inaccuracies. APP can help you establish what kind of approval you will have.
- Once you have given an interview, some organisations will allow you to pull out if you don’t like the final piece, but others will not.
- The journalist whom you work with is unlikely to have any control over the headline of the piece. We can make some points for journalists to pass on to their editors and urge them strongly to avoid certain words. Some will take account of these and others not.
- Some editors will correct factual inaccuracies, or print apologies if information is incorrect, but these are rarely as eye catching as the original story. In rare circumstances editors might agree to edit or remove a piece from their online content, but this would be highly unusual.

The Support you can expect from APP

- APP Trustee & Media Expert (Lucy Vernall) will act as a mediator where necessary between you and the journalist. If we put you in touch with a journalist, Lucy will have spoken to the journalist first to establish that it is a suitable opportunity. Lucy will then contact you after each discussion you have with the journalist for a ‘debriefing’. Lucy will be available on the phone to discuss any issues you have or if you need support with anything. Lucy will liaise with the journalist before and after the piece becomes public and help to resolve any issues.
- If you are contacted directly by a journalist, Lucy is available to support you through the process. Please contact her as soon as you can after contact from the journalist.
- If you personally know any journalists, editors, TV producers etc who might be willing to support us in raising awareness of PP, please let Lucy know.
- We expect that the level of support needed will vary depending upon each person's individual needs and the type of piece, for example, pieces in the local newspaper might require less input from Lucy than national pieces or pieces linked to APP Campaigns.
Creating your Case Study

We ask our Media Volunteers for some details about themselves and their experiences of Postpartum Psychosis (as a sufferer, partner, family member or friend) in order to create a Case Study that can be given to journalists. We will not share your information with a third party without asking you first.

There is a form to complete on our website or within this pack. If you have any questions, or would like help to complete it, please get in touch with Lucy Vernall, our Media Coordinator, by email or telephone. You can send us this information using our online form at www.app-network.org/mediapanel or using the contact details on the inside front cover of this pack.

Once we receive your details, Lucy will contact you by telephone within 2 weeks to discuss the type of media opportunities you would be happy to be involved with. We will then store your details and preferences confidentially on our media panel database.

Lucy will work closely with you by telephone and email to help you put together your Case Study. This will include a brief summary and longer version of your personal story for journalists. You may find you need a couple of telephone appointments to ensure that you are happy with your Case Study. APP will then create a 1 page document, which will include key facts such as: your age, location, how many children you have, when you experienced PP, the type of care/treatment you received, a summary of your personal story, the types of media opportunities you would like to take part in, and how you would like to be contacted. With your permission, the Case Study can also include a photograph.

Media opportunities

Once you are on our Media Panel, we will contact you with any media requests that we think might interest you. Lucy is available to discuss these opportunities further with you. If you agree, we would usually put the journalist in touch with you directly unless you ask us to act as a mediator. Lucy can support you on the telephone both before (planning) and after your interview with the journalist (debriefing). Lucy will also work closely with the journalist until the article is published or the interview goes on air, and will contact you to talk about your feelings on the final piece.

After being interviewed by a journalist, or seeing a piece in press, as well as a debriefing on the telephone with Lucy, you might want to organise to talk through the experience with a friend, or talk to others online at www.app-network/pptalk

It can be quite an exciting and yet stressful experience, so it’s good to have thought about the support you would like in place ahead of time.

Relevant media opportunities can be few and far between, so we apologise if a long time passes between writing your case study with Lucy and receiving a media request. Also, sometimes when we do receive a request the turnaround time will be very quick.

Please contact us at any time with your own media contacts that might be useful, or regarding ideas for media pieces (e.g. local radio features, articles in local newspapers/magazines or letters to the press about any PP articles featured). We can help you organise these and support you through the process.

Can I opt out?

It is up to you to decide which opportunities you would like to take part in – don’t feel compelled in any way to take part in something because we have asked you. You will always have the right to decline if you do not feel comfortable with an opportunity.

You can pull out of any opportunity if you are not happy after meeting or talking to the journalist, even if you have initially agreed. Lucy will help you to understand the point at which you can no longer pull out (for print media this is often after you have done an interview with a journalist, or for TV after you have been filmed.)

You can ask us to remove you from the Media Panel at any point and we will delete your stored information.
APP Media Volunteer Case Study

Name:

DOB:

Brief summary:

Attach a photo here

Detailed story (continue on separate sheets if you would like – this is your story – tell it how you want to)

Key facts

Age:
Ethnic Origin:
Town / County:
Occupation:

No of Children:
Ages of child(ren):

Year of PP episode(s):

Types of Media:

Contact Details:
Name: Naomi Gilbert

DOB: 03/12/1975

Detailed story (continue on separate sheets if you would like – this is your story – tell it how you want to)

I began my career as a Speech & Language Therapist in the NHS. Following a difficult time with anxiety and depression I became involved in psychological therapies research in my 20's. I started my family at 29 and had heard about postnatal depression. I had not heard of Postpartum Psychosis, and neither my husband nor I was aware of the early warning signs.

I had my daughter in November 2005 and within 10 days was hospitalised with symptoms of extreme high mood, and delusions that the world was going to end peacefully and I would help to bring about a new world order. I was treated away from my baby, as there is no Mother and Baby Unit in either Devon or Cornwall within travelling distance. I was in hospital for 3 weeks and then received intensive home treatment support from a team including a mental health social worker and health visitor for some time.

I experienced a period of severe depression in the year following and required further psychiatric admissions due to suicidal intent.

I made a full recovery and went on to become an anti-stigma trainer for Rethink Mental Illness as part of the Time to Change campaign.

In 2010 I made the decision to have another child, and in 2011 my second daughter was born. I had rapid treatment for the early signs of PP and thankfully this did not escalate. I then experienced postnatal depression again and made a full recovery in 2012.

Further information on Naomi's story can be found at: www.time-to-change.org.uk/blog/postpartum-psychosis-mental-illness-after-childbirth

Key facts

Age: 37
Ethnic Origin: White British
Town / County: East Devon
Occupation: Service User Research Consultant
No of Children: 2
Ages of child(ren): 2 & 7
Year of PP episode(s): 2005 & 2007
Types of Media: All

Contact Details:
E: naomi@app-network.org
Mobile: xxx xxxxxxx
Home Tel: xxxx xxxxxx

Brief summary:

- Naomi experienced PP in 2005 and 2011 after the birth of her daughters
- She was separated from her children for both hospitalisations due to the lack of a local Mother and Baby Unit (MBU)
- She is now a Trustee of Action on Postpartum Psychosis and a passionate campaigner for improved services and reduced stigma for postnatal mental illness
Agreeing to be interviewed: Issues to consider

When you are first contacted by a media organisation, make sure you have all the information you need before agreeing to be interviewed. To decide whether you want to do the interview, you might want to ask:

- What is the subject and focus of this particular interview and why did the reporter contact you?
- Which news outlet does the reporter work for and who is its audience?
- Why does the journalist want to do the piece? What type of content have they produced before? Does the journalist have knowledge of PP? Do they have any personal experience of PP or mental illness generally, or do they know anyone that has experienced it?
- Where else might the piece be available? Will it be published online and for how long?
- Where and how will the interview be conducted (in person, on the phone, in a studio, for radio, television, online etc) and how long will it last? Don’t assume that the person you initially talk to will be the person conducting the interview.
- What’s the deadline? News items may need a very quick turnaround.
- For radio and television, will the interview be live or pre-recorded?
- Is this a longer feature or a shorter news piece?
- Will you be the only interviewee or is it a discussion/panel interview? Will there be calls taken from the public?
- Does it fit in with your own and APP’s aims and media strategy?
- Are they happy to mention APP and give our contact details?
- May APP have a copy of the piece or link to it from our website?

Preparing for the interview: Sharing your story

Preparation is key to helping you feel more confident and in control for whichever type of media you engage with. Talking through your story with Lucy will help you to organise your thoughts and identify the key messages you want to get across. Here are some other things to consider…

- It helps to think of an interview, particularly for radio or television, as a conversation but with other people listening in. Talk directly to the host/reporter instead of imagining the listening/watching audience.
- Think first about how to deal with very open questions such as ‘tell us your story’ or ‘what happened to you’? Offer a concise summary of your experiences, rather than launch into the whole story at this point.
- To avoid drying up, write notes or keywords about the points you want to make, but avoid memorising a script.
- Consider the most difficult questions the interviewer could ask you and think about how you can best answer them.

Preparing for the interview: Feeling confident

- Remember that you will almost certainly know more about the subject than the reporter/host so don’t be afraid to (nicely) put them right if they make an assumption or start to take the interview in an unhelpful direction.
- Have useful statistics to hand (see the Facts & Figures section of this guide) and useful websites/telephone numbers of organisations like APP.
- Staying in control. This is your chance to get your message across. You don’t want to come away from the interview feeling you haven’t talked about the most important points for you. You can find a way to say what you want irrespective of the question asked. If an interview seems to be going off-track it can be helpful to have some stock phrases such “That’s an interesting question, but what’s really important is…” or ‘The real question/point is….’
• Decide beforehand if there are subject areas that you do not want to discuss. Keep a list in front of you and consider the reasons that you do not want to discuss them. It can be useful to think of some phrases like “What the research tells us is...”, “Some women who experience PP report experiences like that, but it’s different for everyone”. You might want to directly explain why you don’t want to answer a particular question “Sadly there is still stigma regarding the experience and so…” or “It’s not something I can talk about publicly yet - as my children grow older I would like to find the right words to tell them about it.” If you would like to practise some of these strategies before an interview, we can arrange for you to do this with Lucy over the phone.

Identifying your key messages

• Try coming up with a Single Sentence Summary (SSS) and practise explaining your main point in one sentence.
• Flesh out your single sentence summary with no more than 3 points.
• Practise to get really confident with your 3 key messages. Revisit 3 key messages during the interview to avoid irrelevant questions/diversion.
• For print interview, ask the journalist to read notes back to you during the interview if you want to make sure a point has come across in the way you intended.

Your image

• Do they want you to send photos? If you are asked to send photos, you should make sure that you have the rights to let someone else use them. Whoever took the photo usually owns the copyright.
• Will a photographer come to you? Do they plan to do your makeup? You might want to ask whether you can obtain a copy of the photos for yourself.
• Consider the type of photo they are setting up – where are you, who are you with, how are you posed? Are you happy with being portrayed in this way? If not, negotiate a setup that you do feel happy with.
• If the piece is for television, take the studio make-up if offered!
PP briefing:
key facts & figures

We like to ensure that APP Media Volunteers and journalists working with us have the most up to date and accurate facts and figures on Postpartum Psychosis. When preparing for an interview you could also talk to Lucy about APP initiatives which we are trying to publicise, check the News section of the APP website, and refresh yourself on our FAQ’s www.app-network.org/what-is-pp/faq

• APP is a registered charity which aims to: increase awareness of Postpartum Psychosis (PP) among health professionals and the general public; provide support and information to women and their families affected by PP; facilitate research into all aspects of PP; and campaign for improved services for women and their families.

What is PP?

• Postpartum Psychosis is an episode of severe mental illness that normally begins in the hours, days or weeks after having a baby, and escalates rapidly.

• Episodes of PP follow around 1–2 in 1000 deliveries. An average sized maternity unit would see 8–10 cases in a year. Around 1400 cases occur each year in the UK.

• PP can occur to women from all social classes, occupations, and educational backgrounds. Often it occurs without warning, ‘out of the blue’ to women without any previous psychiatric history.

• PP is not a form of Postnatal Depression.

• Symptoms include psychosis (loss of contact with reality – including hallucinations - hearing, seeing, feeling & smelling things that could not be there; or delusions – these are odd beliefs that have no basis in reality, such as the mother has special healing powers, the TV is talking about her, the baby is sent from God, people are watching or following her, etc).

• Symptoms often include mania (elation or euphoria, grandiosity, rapid thoughts and speech, not needing to sleep etc); depression (low mood, slowed movements or thinking, loss of self esteem, etc); rapid mood changes (between mania and depression); severe confusion (perplexity, not being able to organise thoughts); anxiety and agitation. Behaviour can be very bizarre and episodes can be very frightening for women and their families.

• Common early warning signs include sleeplessness, euphoric or high mood, talking/writing alot, racing thoughts, increased sociability, feeling irritable/impatient, anxiety and excessive worries, increased spirituality.

• The postpartum period is a devastating time for women to experience a mental illness. Mothers can feel loss, guilt, responsibility for missing out on the early months of motherhood. Fathers may become fully responsible for a newborn or may be separated from their families, not knowing if their partners will fully recover.

• Stigma and sensationalism in the media can contribute to mothers’ feelings of isolation and to difficulties in discussing their experiences with other mothers. Often, when women and their partners search the Internet for information, alarmist stories about mothers harming their babies are the first they encounter. Friends and professionals can help by searching the Internet for information and pointing individuals to useful sites, whilst screening out the scary information.

Treatment

• PP should always be treated as a psychiatric emergency and usually requires hospital admission.

• Most women with PP need treatment with medication. This is usually an antipsychotic, a mood stabiliser or both.

• The majority of women with PP are unable to seek help for themselves and others must obtain help for them.

• Some areas of the UK have specialist perinatal mental health services which can support women at high risk during pregnancy and after birth.

• Some areas of the UK have inpatient Mother & Baby Units. See our map for current MBU locations www.app-network.org/what-is-pp/getting-help/mbus

• There are only about half as many beds as are needed in MBUs. Research carried out by APP suggests that mothers make a significantly faster recovery and feel more bonded with their baby when treated in a MBU in comparison with a general adult psychiatric ward.
Prognosis

- With early recognition and treatment women make a full recovery.
- The most severe psychosis symptoms tend to last 1–3 months, but can be followed by a period of depression. Recovery can be a gradual process taking 12 months to 3 years.
- Some women may have further episodes of illness, particular Bipolar Disorder, at a later time.
- Postpartum Psychosis is a leading, but preventable, cause of suicide in mothers.
- Unidentified or poorly managed PP presents a risk to child safety during the acute psychosis and later depression phase. Cases of infanticide do occur but are an extremely rare outcome of PP.
- There is no evidence that PP is associated with poorer mother-baby attachment or developmental problems for the infant.

What causes PP?

- PP is not associated with relationship problems, social or financial circumstances, or the baby being unwanted (unlike Postnatal Depression).
- We know that genetic factors are important. You are more likely to have Postpartum Psychosis if a close relative has had it. Work is ongoing at Cardiff University conducted by Dr Ian Jones – APP supports recruitment to these important studies.
- Changes in hormone levels and disrupted sleep patterns may also be involved. PP is more likely after first deliveries. There is recent evidence of a possible link with pre-eclampsia.
- The causes are not well understood. More research is desperately needed.

Who is at risk?

- Many women experience Postpartum Psychosis with no previous history of mental health problems (approximately half of all cases of PP).
- Women with a history of Bipolar Disorder are at significantly higher risk of Postpartum Psychosis (around 50% risk, in other words 1 in every 2 women).
- Women with a first degree relative – mother or sister – with Postpartum Psychosis are also at increased risk (3% risk, in other words 3 in every 100 women).
- Women who have had one episode of Postpartum Psychosis have a high risk in subsequent pregnancies (around 50% risk, in other words 1 in every 2 women).

End The Stigma

We are not ‘insane’, ‘mental’, ‘mad’ or ‘dangerous’...
We are ordinary mums, recovering from Postpartum Psychosis

www.app-network.org

#PPTalk
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