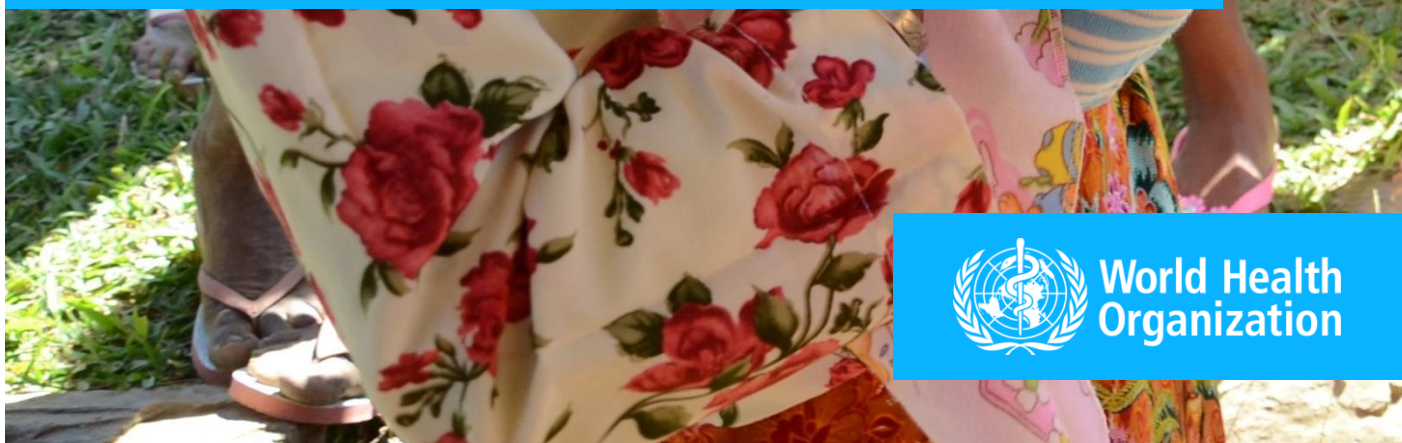




Psychosocial support for pregnant women and for families with microcephaly and other neurological complications in the context of Zika virus

Interim guidance for health-care providers



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Introduction

On 1 February 2016 WHO announced that a cluster of microcephaly (1) and other neurologic disorders reported in Brazil is a Public Health Emergency of International Concern. Several countries have reported an increase in the incidence of cases of microcephaly and/or Guillain-Barré syndrome (GBS) (2) concurrent with Zika virus outbreak (3). A causal relationship between Zika infection during pregnancy and microcephaly is strongly suspected, though not scientifically proven (4).

This document describes guidance for a supportive response by healthcare providers (e.g. physicians, nurses), focusing primarily on women affected by Zika virus infection during pregnancy and their families, for their mental health and psychosocial needs.

Healthcare workers need to collaborate with colleagues in other sectors (e.g. social work, education) for a coordinated mental health and psychosocial response.

This guidance for healthcare providers suggests strategies that can be helpful when consulting with the following groups of women and their families:

- Pregnant women with suspected or confirmed Zika virus infection
- Pregnant women who know they carry a child with suspected microcephaly
- Caregivers and families of an infant with microcephaly

When caring for pregnant women, it is important to involve trusted people who can support them. These may be the woman's partner, her friends or family members. Bear in mind that these people may need psychosocial support as well.

Psychosocial support for other neurological conditions

Although this document is focused on microcephaly, many of the described supports (e.g., providing accurate information, supportive communication, providing basic psychosocial support, strengthening social supports, managing concurrent mental disorders) also apply to other neurological conditions - such as Guillain-Barré syndrome - that may be potentially associated with Zika virus.

1. Accurate Information

All healthcare providers need accurate information when providing support to women with Zika virus infection during pregnancy

Providing accurate information about a largely unknown communicable disease and its suspected effects is important not only for public health reasons (5) but also because it can reduce anxiety in people and their communities. However, different agencies and different media channels often provide information that may be inconsistent or contradictory. Unverified but plausible-sounding rumours communicated through social media can cause serious distress. New information about the Zika virus and its effects on pregnant women, fetuses and infants, and GBS and other neurological complications will become available over time. It is important you keep yourself updated on this information at all times.

You should also know about other services available to women and families affected by Zika virus infection during pregnancy and/or microcephaly. These may include antenatal and postnatal home visits for women with special needs, health services for assessment of an infant with microcephaly and management of neurodevelopmental disorders, hearing and visual impairment, psychological interventions, women's support groups, parent and community support groups, community-based rehabilitation services and social and educational services for children with disabilities. You should also be aware of any services available for persons with GBS and their families.

- Be up to date with the latest scientific information on the Zika virus and its potential consequences.
- Be aware of the latest guidance on assessment and management of Zika virus and its potential consequences.
- Get acquainted with available services and support / referral systems for people and their families affected by Zika virus infection during pregnancy and/or microcephaly.

2. Conveying health information

Health information should be conveyed in a manner that considers people's well-being

The diagnosis and management of microcephaly and other neurological disorders are immediate concerns for healthcare providers. **The way a healthcare provider assesses and manages these health conditions can have an impact on the psychosocial well-being of patients and their families.** As stigma is a concern, it is important to ensure confidentiality of any information and care provided. The steps below should be considered for protecting and promoting psychosocial well-being in the context of regular physical health care of Zika infection in women during pregnancy and/or microcephaly. Where possible, invite a trusted partner or family member to attend the session. This will help them to learn about the relevant health condition and is an opportunity to encourage them to be supportive. It is important to allocate sufficient time within healthcare sessions to properly implement the steps below.

- Provide accurate and understandable information (see Section 1 on accurate information) on all assessments and investigations before they occur and on the results of those tests.
- Ask the person about what they know about Zika and/or microcephaly or other neurological complications. Take the time to listen to the person's and their partner's/family members' reactions (thoughts, feelings) to the results.
- Educate the person on what you know about the prognosis of Zika and/or microcephaly or other neurological complications.
 - It is important to emphasize that many babies with microcephaly do not develop developmental disorders or other severe neurological complications.
- Check with the person to see if they have understood test results and their implications. Ask them to summarize their understanding of what you have conveyed. Correct gently if there is any misunderstanding.
- Throughout the care, encourage the person and their family members to take notes and to return to the clinic if they have further questions.
- Explain the need for regular follow-up care to monitor neurodevelopment and assess for possible complications.
- Share information about, and refer people to, relevant services to address social, psychological and physical health needs, as appropriate.
- Educate about appropriate measures to control spread of the virus (such as male and female condoms, mosquito repellent safe for use during pregnancy, and insecticide treated bednets).
- Before ending each session, restate and confirm what the next action step is for the person, such as attending another appointment or contacting a service.

- Encourage women to involve and invite a trusted person (partner, friend, family member, or friend) to the session or to any follow-up sessions.
- Ensure confidentiality of any care provided.
- Emphasize that many babies with microcephaly do not develop developmental disorders or other severe neurological complications.

3. Supportive communication

The way you communicate with women and families affected by Zika virus and/or microcephaly or other neurological complications is very important.

They may be confused or feel upset, anxious or angry (see section 4 on psychological reactions). You should try to use simple language, and avoid technical terms to ensure that they understand the information you give them.

Being calm and showing understanding can help people in distress feel more understood, respected, cared for appropriately, and empowered to make informed decisions and plans. However, some healthcare providers lose their good communication skills when they are with someone who is acutely distressed. Health care providers may not communicate well when under the pressure of time or overworked. This is especially common during epidemics.

Listening to someone can be a great support. It is, however, important not to pressure anyone to share their story with you. Some people may not want to speak about their circumstances. However, they may value it if you stay with them quietly; let them know that you are there when they want to talk. Don't talk too much, allow for silence. Keeping silent for a while may give the person space and encourage them to share with you if they wish. In Box 1 you can find suggestions for things to say and do, and what not to say and do. Most importantly, be yourself, be genuine and be sincere in offering your help and care.

Box 1. Do's and don'ts of supportive communication (adapted from WHO et al, 10)

DO'S

- ✓ Try to find a quiet place to talk, and minimize outside distractions.
- ✓ Provide actual information, if you have it. Be honest about things you know and don't know. "I do not know, but I will try to find out about that for you and will let you know as new information on this becomes available."
- ✓ Let them know you are listening; for example, nod your head or say: "hmmmm....."
- ✓ Be patient and calm.
- ✓ Give information in a way that people can understand- keep it simple.
- ✓ Respect people's right to make their own decisions.
- ✓ Be aware of and set aside your own biases and prejudices.
- ✓ Make it clear to people that even if they refuse help now, they can still access help in the future.
- ✓ Respect privacy and keep the person's story confidential, if appropriate.
- ✓ Acknowledge the person's strengths and how they have helped themselves.
- ✓ Allow for silence.
- ✓ Make sure you understand what people say by repeating what you understood to them, and asking them if you understood them correctly.
- ✓ Behave appropriately by considering the person's culture, age and gender.
- ✓ Be sensitive. Acknowledge how they are feeling about things: "I am so sorry. I can imagine this is very sad for you".

DON'TS

- ✗ Don't pressure someone to tell their story.
- ✗ Don't take away the person's strength and sense of being able to care for themselves.
- ✗ Do not blame the person for becoming pregnant.
- ✗ Do not blame the person for not using insect repellent.
- ✗ Don't interrupt or rush someone's story (like looking at your watch or speaking too rapidly).
- ✗ Don't make up things you do not know.
- ✗ Don't feel, think and act as if you must solve all the person's problems for them.
- ✗ Don't use overly technical terms.
- ✗ Don't give false promises or false reassurances.
- ✗ Don't feel you have to try to solve all the person's problems for them.
- ✗ Don't tell them someone else's story.
- ✗ Don't judge what the person has done or has not done, or how they are feeling. Don't say..."You shouldn't feel that way".
- ✗ Don't talk about your own troubles.

4. Common reactions

People may react in various ways to being affected by Zika virus and its potential consequences

In normal times, on average one in five women presents symptoms of distress during pregnancy or after childbirth. Women who have contracted Zika virus infection during pregnancy and/or who are told their child may have or has microcephaly may be even more likely to develop symptoms of distress. Some examples of symptoms of distress are listed below:

- Irritability, anger
- Guilt, shame
- Insomnia, nightmares
- Physical symptoms (shaking, headaches, feeling very tired, loss of appetite, aches and pains) without an organic cause
- Crying, sadness, depressed mood, grief
- Excessive worries, anxiety, fear

In addition, to minimize their stress, women may engage in unhealthy behaviours, such as tobacco and alcohol use.

Some of the above-mentioned psychological reactions are also common and normal during pregnancy, such as feeling very tired or having sleeping problems. In women experiencing psychological distress, physical symptoms such as headaches may worsen.

The partner/father or close family may react in similar ways to the stress and uncertainties of the situation and the unknown future of the child and the effect it will have on the family.

There will be people with severe symptoms of psychological distress, who need more than the support you can give them. Their symptoms are considered severe if they cannot function in their daily lives or if they are a danger to themselves or their children. They may have difficulties caring for themselves or their children.

- Depression and other mental disorders should be considered in women who are *not functioning well in daily activities because of their distress for a prolonged period of time* (e.g. more than 2 weeks) (6, 7) Healthcare workers should monitor for depression during antenatal and postnatal visits. Depression in pregnant women can be managed effectively with psychological treatments ¹ (e.g., 8). Antidepressant medicines should be avoided, especially during the first trimester.
- Make sure that people in danger to themselves or others are not left alone. Stay with them until you organize help from relevant services.

Unless you are trained to assess and manage severe symptoms of distress, you should refer people with severe symptoms of distress to specialized care.

¹ WHO recommends interpersonal therapy and cognitive behaviour therapy as treatments for depression.

5. Basic psychosocial support

A key feature of basic psychosocial support to women who are afraid of microcephaly is asking about their needs and concerns and trying to help to address these.²

- Ask about people's needs and concerns around
 - Pregnancy and having had Zika virus,
 - Carrying a child with microcephaly, or
 - Having a child with microcephaly
- Listen to them carefully. Try to understand what is most important to them at this moment, and help them work out what their priorities are.
- Help people address urgent needs and, where possible, their concerns
- Give accurate information (see Section 1 on accurate information)
- Help people with any decision-making, as necessary
- Help connect people with loved ones and social support (see Section 6 on strengthening social support)
- If feasible, consider discussing with women affected by Zika how they can help one other.
- If relevant, teach people basic stress management techniques (see Section 7 on stress reduction)

Provide basic psychosocial support, using the above principles, to people with GBS and other neurological complications.

Always ask about any other needs or concerns the person may have. Do not presume that Zika and its possible consequences are people's main worries. They may have other concerns such as financial and family problems, including domestic violence, as well as other health problems, including mental health problems. Link these people to the relevant services and supports to address these needs and concerns.

² The approach described here is consistent with psychological first aid (10).

6. Strengthening social support

People tend to cope better when they have friends, family members, or community groups that offer care and support. If the woman has a partner, it is usually helpful to include that person in the discussion to encourage supporting each other.

A person does not necessarily need many social supports, but they do need someone who can be helpful to them and provide support in their specific situation. Sometimes, emotional distress can affect a person's ability to get support when they need it.

Consider saying the following to the person:

"I would like to help you strengthen your social support. For some people, social support means sharing their difficulties and feelings with other people they trust. Or it might just be helpful spending time with friends or family and not talking about problems. For others, it might be using resources from trusted people such as knowledge that is needed to get something done. And for others, still, it might mean connecting with community organizations or agencies to get support. These forms of social support can be very powerful in reducing distress. Is there some way you think you might be able to strengthen your social support?"

Help the person to decide in what way they want to strengthen their social support, for example, by talking to someone, by getting more practical help, such as support with taking care of other children in the family, run errands, or connecting with another agency or community organization. If the person is not sure about strengthening their social support, even though you have reason to believe they need to, you may want to discuss this further.

You may say:

"Many people feel unsure about talking with others about their problems or asking others for help. One reason is because they are worried they will burden the other person with their problems. This is often not true though. People will often share problems when they hear their friend also tell them about their own problems. Or they might ask for help in return. This might be because that friend is also experiencing similar or other problems. In general, there are many people who are happy to listen and try to help. It can also be helpful hearing other people's difficulties so you get a perspective about your own issues especially if you think you are the only one experiencing a problem."

Help the person to identify supportive and trusted family members, friends and community members and to think through how each one can be involved in helping.

"Another reason people do not get support from others is because they have no one they trust. If you think you don't have anyone you can trust, shall we discuss more together about finding someone in your family or community that you can trust?"

7. Stress reduction

The person's concerns about their pregnancy and their baby might cause them a lot of stress. Concerns about Zika in pregnant women and/or microcephaly may also cause social problems in families and communities (e.g. stigma, discrimination, abandonment). You can use the following strategies to help them reduce stress.

Encourage coping through problem solving

- Link the woman to social services and resources in the community to address any social problems that can be addressed by the social sector
- Use problem-solving techniques to help the person address major stressors, such as discrimination. Work together with the client to brainstorm solutions and coping strategies for identified problems, prioritize them, and discuss how to implement these solutions and strategies.
- When stressors cannot be solved or reduced, problem-solving techniques may be used to identify ways to emotionally cope with the stressor. In general, do not give direct advice. Try to encourage the person to develop their own solutions.

Discourage tobacco, alcohol and drug use as a way of coping

- Tobacco, alcohol and drugs should be avoided during pregnancy and in breastfeeding mothers because they are harmful for their babies
- Tobacco, alcohol and drugs can cause a range of health problems. A commonly held myth is that alcohol is helpful for mental health. Indeed, people often use alcohol and other substances as a form of self-medication. However, it does not help solve problems and its use often causes social and health problems.
- For tools on assessment and motivational interventions to reduce alcohol and other substance use, see WHO ASSIST package (9).

Encourage positive coping

- Everyone has natural ways of coping. Encourage people to use their own positive coping strategies, while avoiding negative strategies (see Box 2). This will help them to feel stronger and regain a sense of control.

Box 2. Examples of coping strategies (10)

Encourage positive coping strategies

- ✓ Get enough rest
- ✓ Eat as regularly as possible and drink water
- ✓ Talk and spend time with family and friends
- ✓ Discuss problems with someone you trust
- ✓ Do activities that help you relax (walk, sing, pray)
- ✓ Do physical exercise

Discourage negative coping strategies

- ✗ Don't take drugs, smoke or drink alcohol
- ✗ Don't sleep all day
- ✗ Don't work all the time without any rest or relaxation
- ✗ Don't isolate yourself from friends and loved ones
- ✗ Don't neglect basic personal hygiene
- ✗ Don't be violent

Teach stress management

- Identify and develop positive ways to relax (e.g. listening to music, playing sports). Ask: "What are some of the things that give you comfort, strength and energy?"
- Teach the person a specific stress management technique; breathing exercises (See Box 3). Encourage the person to regularly practise this strategy, and use it in response to feelings of anxiety and stress.

Box 3. Relaxation exercise: instructions for slow breathing technique

I am going to teach you how to breathe in a way that will help relax your body and your mind. It will take some practice before you feel the full benefits of this breathing technique.

The reason this strategy focuses on breathing is because when we feel stressed our breathing becomes fast and shallow, making us feel tenser. To begin to relax, you need to start by changing your breathing.

Before we start, we will relax the body. Gently shake and loosen your arms and legs. Let them go floppy and loose. Roll your shoulders back and gently move your head from side to side.

Now place one hand on your belly and the other hand on your upper chest. I want you to imagine you have a balloon in your stomach and when you breathe in you are going to blow that balloon up, so your stomach will expand. And when you breathe out, the air in the balloon will also go out. Watch me first. I am going to exhale first to get all the air out of my stomach.

[Demonstrate breathing from the stomach – try and exaggerate the pushing out and in of your stomach]

OK, now you try to breathe from your stomach with me. Remember, we start by breathing out until all the air is out; then breathe in. If you can, try and breathe in through your nose and out through your mouth.

Great! Now the second step is to slow the rate of your breathing down. So we are going to take three seconds to breathe in, then two seconds to hold your breath, and three seconds to breathe out. I will count with you. You may close your eyes or keep them open.

OK, so breathe in, 1, 2, 3. Hold, 1, 2. And breathe out, 1, 2, 3. Do you notice how slowly I count?

[Repeat this breathing exercise for approximately one minute]

That's great. Now when you practise on your own, don't be too concerned about trying to keep exactly to three seconds. Just try your best to slow your breathing down when you are stressed.

OK, now try on your own for one minute.

When people excessively worry about Zika and/or its consequences, provide them with basic tips for minimizing excessive worrying (see Box 4).

Box 4: Basic tips to minimize excessive worrying about Zika and/or microcephaly

- Ask worried people to select a half-hour worry period, allowing themselves to worry as much as they like within that period but not during the rest of the day.
- Ask people to use a “thinking stop” when worries pop up in their head that they cannot do anything about at that time. Ask them to write down those thoughts and postpone them to the next worry period. People can thus choose to interrupt their negative thoughts and try to think about something else.

Advise people that during their worry periods they can worry as much as they like but they should also ask themselves what they can change and commit to taking some action. (For example if they have worries due to a lack of information about Zika, the health status of their unborn baby, or what other services that are available, you should help them make a plan about how to gain this information.)

8. Advice on parenting

During pregnancy: for pregnant women with Zika virus infection

- Assist the mother preparing for life with a baby. Support the creation of joyful and positive expectations about the relationship with her baby and building confidence in her ability to provide care. Involve the father and family as much as possible; encouraging them to support the mother.
- Remind the expectant mother that many babies born to mothers exposed to Zika virus infection during pregnancy do not have microcephaly, and that many children with microcephaly may not develop developmental disorders or other severe neurological complications.
- Provide basic psychosocial support, including stress reduction and strengthening of social supports.

After child birth: for mothers of children with microcephaly without evident neurological complications

- Help the mother become aware of her baby's positive characteristics and build her confidence in caring for the baby.
- Remind the mother that many children with microcephaly do not develop developmental disorders or other severe neurological complications.
- Model a positive and caring attitude towards the child with microcephaly.
- Counsel on breastfeeding.
- Emphasize the importance of play and communication activities for promoting infants' and children's development throughout childhood (see Box 5 for age-appropriate activities) (12). Involve fathers/other caregivers as much as possible.
- If the mother or primary caregiver presents significant psychological distress, help identify a person who can assist her with taking care of the baby.
- Provide basic psychosocial support, including stress reduction and strengthening of social supports
- Offer further assessment and follow up care for developmental monitoring to all children born with microcephaly.



Recommendations for Care for Child Development



**NEWBORN,
BIRTH UP TO 1 WEEK**

**1 WEEK UP
TO 6 MONTHS**

**6 MONTHS
UP TO 9 MONTHS**

**9 MONTHS
UP TO 12 MONTHS**

**12 MONTHS
UP TO 2 YEARS**

**2 YEARS
AND OLDER**

**Your baby learns
from birth**



PLAY Provide ways for your baby to see, hear, feel, arms and legs freely, and touch you. Gently soothe, stroke and hold your child. Skin to skin is good.



COMMUNICATE Look into baby's eyes and talk to your baby. When you are breastfeeding is a good time. Even a newborn baby sees your face and hears your voice.



PLAY Provide ways for your child to see, hear, feel, move freely, and touch you. Slowly move colourful things for your child to see and reach for. *Sample toys: shaker rattle, big ring on a string.*



COMMUNICATE Smile and laugh with your child. Talk to your child. Get a conversation going by copying your child's sounds or gestures.



PLAY Give your child clean, safe household things to handle, bang, and drop. *Sample toys: containers with lids, metal pot and spoon.*



COMMUNICATE Respond to your child's sounds and interests. Call the child's name, and see your child respond.



PLAY Hide a child's favourite toy under a cloth or box. See if the child can find it. Play peek-a-boo.



COMMUNICATE Tell your child the names of things and people. Show your child how to say things with hands, like "bye bye". *Sample toy: doll with face.*



PLAY Give your child things to stack up, and to put into containers and take out. *Sample toys: Nesting and stacking objects, container and clothes clips.*



COMMUNICATE Ask your child simple questions. Respond to your child's attempts to talk. Show and talk about nature, pictures and things.



PLAY Help your child count, name and compare things. Make simple toys for your child. *Sample toys: Objects of different colours and shapes to sort, stick or chalk board, puzzle.*



COMMUNICATE Encourage your child to talk and answer your child's questions. Teach your child stories, songs and games. Talk about pictures or books. *Sample toy: book with pictures*

Box 5. Tips to promote child development (12)

- Give your child affection and show your love
- Be aware of your child's interests and respond to them
- Praise your child for trying to learn new skills

After childbirth: for mothers of children with both microcephaly and neurological complications (e.g. developmental disorders, epilepsy) (6)

- Help the mother become aware of her child's positive characteristics and build her confidence in caring for the child.
- Model a positive and caring attitude towards the child.
- Inform caregivers about the health conditions and explain the problems.
 - Ask the caregivers' about their explanation for and knowledge of the conditions. Explain that the child's health problems are not the mother's fault and, if relevant, are not related to sins, witchcraft, or other things (see Section 2 on conveying health information about Zika and microcephaly).
- Promote child development.
 - All children, including those with developmental delays and neurological complications, can learn and develop skills. Caregivers can help children develop by engaging with them in everyday activities and play.
- Provide or refer children for further assessment and management of health and neurological complications (feeding difficulties, epilepsy, visual and hearing impairment) as required.
- Inform about other available services, such as community-based rehabilitation and social services.
- If necessary, support the mother to overcome barriers that may prevent her from accessing the care and services she and/or her infant require.
- Provide basic psychosocial support, including stress reduction and strengthening of social supports.
- Offer parent skills training (13) and encourage informal parent support groups.
- Offer or organize follow up care for developmental monitoring to all children born with microcephaly. Offer follow up care for epilepsy or other neurological conditions, as required.
- Promote and protect the human rights of the child and family: be vigilant about human rights, dignity and safety. Try to address any discrimination in collaboration with available social services,

Box 6. Tips on parenting a child with microcephaly and neurodevelopmental complications

- Being a parent, and having a child with microcephaly and neurodevelopmental complications, will bring you many joys but can also be stressful and challenging at times.
- Identifying what is important to you, in your role as a parent, can help guide your actions even when times are difficult. What kind of parent do you want to be for this child? For example, to be protective of my child, to be caring towards my child, to be responsive to his needs, to be playful with my child, to be a good role model.
- You can set small actions to do that are in line with your values. For example, spend some time each day playing with your child.
- Taking care of yourself can be very important and also helps you care for your child and family.

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