Families may be very concerned. Parents are likely to have many questions, concerns, worries, and a range of strong feelings, including sadness, anger, and guilt. People who are struggling with these reactions may find it difficult to concentrate or make even simple decisions—but these families are generally faced with important and sometimes urgent decisions that may seem particularly overwhelming. These reactions may lead some families to avoid following recommendations for screening, testing, evaluation, and monitoring. Your support is going to be important to help families follow through on medical advice.

There is still a lot we don’t know. There is still limited information about the range of outcomes associated with fetal Zika virus infection, and it is particularly difficult to give precise and accurate predictions of risk for an individual family. Guidance is out there. Updated guidance is available from the Centers for Disease Control and Prevention (CDC) at www.cdc.gov/zika. The American Academy of Pediatrics (AAP) offers “Key Information for Pediatricians” at www.aap.org/zikakey. Part of the challenge of supporting families affected by Zika is not feeling sure of what the right next steps in management are. You don’t need to memorize everything about Zika—just know where to find it.

When professionals don’t know what to say, they often choose to say little or nothing. But saying nothing says a lot—it may make families think you are unaware of their concerns or uninterested, unwilling, or unable to be of support. Tell families you hear their concerns and can be a source of support for them.

We are learning more about this virus all the time. New findings are coming out continuously regarding Zika virus, how it is transmitted, and its effects. While there is still much we don’t yet know about Zika virus infection, there is much we do know about other viral agents that infect and damage the central nervous system of fetuses—and this information may give us some important insights.

Your support matters. Parents benefit a great deal from partnering with empathetic and concerned health care providers. While you may not know all the answers, just knowing that you are there to face the questions together—as they arise and throughout their baby’s childhood—can be an enormous support to parents.

Don’t say “Everything will be okay.” While it may be tempting to give blanket reassurance, this is often not helpful and may undermine a patient-physician relationship built on trust. Instead of telling parents they shouldn’t feel worried, help them figure out approaches to deal with their distress. Emphasize that you are here to help and support them when they have questions and need guidance on what to do.

Do say “This is not your fault.” Guilt on the part of parents is likely to be common and should be addressed explicitly. It is important to reassure parents that the infection was not their fault.
Focus on the positive steps. Providing too much information or predicting only the worst-case scenario is not helpful. Try to be realistic in your assessment, but phrase things in terms of positive steps that parents can take to reduce the risk of confusion. For example, enrolling the child in early intervention is critical and can provide parents with skills to help promote their child’s development to the extent possible. Supportive services do not need to be Zika specific. There are a range of services available for families of children with suspected or confirmed developmental disabilities of other causes that may be helpful.

Watch for later problems. Some infants exposed to Zika virus in utero have been born without any obvious birth defects, but then they have demonstrated later-onset issues, such as slowed growth of the head and developmental delays. It will be critical for the child’s primary care provider to follow these children through health supervision visits and developmental screening to identify late manifestations of Zika virus infection. The AAP recommends following CDC Zika guidance (https://www.cdc.gov/zika/hc-providers/) and the Bright Futures Periodicity Schedule (www.aap.org/periodicityschedule) for the most up-to-date screening guidance.

Don’t forget about your own well-being. It can be upsetting to be with patients and families in distress, and the level of uncertainty at this point in time related to Zika virus infection can make it even more difficult. Professional self-care is important. Use trusted resources to get up-to-date information and partner with other members of the health care team and community to help these families—don’t try to do it all by yourself.

This information is accurate as of April 2017. For the most up-to-date information, see the resources below.

Resources
For further information on how to support children and families at times of crisis (which is also relevant for family crisis), you may wish to review the following resources.

- AAP Zika resources pages for health care providers: www.aap.org/zika and www.aap.org/zikakey
- AAP Zika resources page for families: www.healthychildren.org/zikavirus
- American College of Obstetricians and Gynecologists Zika Toolkit: www.agog.org/zikatoolkit
- CDC Zika Web page: www.cdc.gov/zika

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For more information, contact the American Academy of Pediatrics at DisasterReady@aap.org. The AAP acknowledges David Schonfeld, MD, FAAP, for his leadership on this product.

Listing of resources does not imply an endorsement by the American Academy of Pediatrics (AAP). The AAP is not responsible for the content of external resources. Information was current at the time of publication.