

A Pocket Guide for Communicating Newborn Screening Results

Communicating newborn screening results is a critical responsibility that directly affects family understanding, trust, and follow-up. **Families remember what you say - and more importantly - how it makes them feel.** Consistent, clear, and intentional word choice can reduce confusion and anxiety, support timely follow-up, and strengthen confidence in the newborn screening system. This tool provides practical **things to say** to support strong communication and high-quality, family-centered result disclosure across care settings. These tips help you prepare to confidently and compassionately communicate newborn screening results in a patient-centered manner.

1

Open With Context

"As part of the care every baby has after birth, we screen all newborns for certain health conditions. I'm calling about your baby's results and need to discuss them with you today. Do you have a few minutes now, or can we find a time within the next few hours that works?"



Name the Condition

"The screening flagged a possible condition called [condition name]. Let me explain what this result means and what we know so far."

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Acknowledge Emotion

"I understand this may feel overwhelming. It's completely normal to have questions and concerns."



Offer Balanced Reassurance

"Many babies with similar results turn out to be healthy. We only screen for conditions that have treatment options available. Early detection allows us to provide the best care if needed."

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Deliver the Result Clearly

"The screening showed a result that needs follow-up. This doesn't mean your baby definitely has the condition—it means we need to do more testing."



Explain Next Steps Clearly

"Here's what happens next: We would like to refer you to ____/ send you for follow up testing on _____. Is there anything that will make it difficult for you to get there?"

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Address Urgency Without Alarm

"While this screening result does not confirm a diagnosis, it is important to follow up quickly. There are treatments available for this condition, so, getting results quickly helps us make sure your baby receives care right away if it's needed."



Check Understanding

"I've shared a lot of information today. Just to make sure I explained this clearly, what will you tell your family/friend about today's call?"

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Close With Support

"You're not alone in this. Our team is here to support you every step of the way. Here's how to reach us with any questions."



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When screening results are shared without careful language, families can feel frightened, confused, or unsure of what to do next – sometimes leading to delayed care for their newborn. The words you choose in this moment help families feel steady, informed, and ready to take the next step. Below are suggestions of **things to avoid** when sharing newborn screening results with families.

1

Vague Descriptions

Using abbreviations, acronyms or other inaccurate references to newborn screening such as "the PKU test."



Explanation without Context

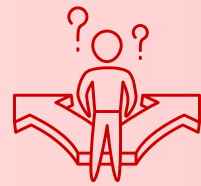
"Your baby's result is 'abnormal.'" or "Your baby 'failed' their newborn hearing screen."

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Minimizing Results

Avoid dismissive phrases like "don't worry" or "this is probably nothing".



Rushing

Avoid calling when you have limited time to properly disclose the newborn screening results. "I only have a few minutes."

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Overly Alarming

Avoid overly scaring families. Without clear guidance on next steps and when, families may equate "needs follow-up" with immediate danger.



Unclear Next Steps

Avoid vague endings and unaddressed questions like "We will be in touch soon."

6

Checklist for Successful Results Delivery

Prepare: Ensure time for the call (don't rush) and prepare what you plan to share.

Clarify: Confirm specific result and have next steps/recommendations ready.

Listen: Ask questions often to assess both the family's knowledge and emotional responses.

Support: Provide specific contacts for specialists, share trusted resources, and offer a follow-up phone call.

