

Tele Program

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Part 2 How To Follow Up With the Doctor – Building a Successful Healthcare Relationship

Katherine Thoman, CNP and Abby Nye, MD.

## Questions

Is it appropriate to email your provider?

- Yes, but not if the concern is urgent and would have to be answered immediately. If it is urgent call the office.
- When using email for a question that will be answered in person at the next visit take a copy of your email with you as the provider may not have the email with them.
- Make sure that you check with your provider before you email. Some providers are just not savvy about email and prefer to have you call the office. Just make sure ahead of time that it is ok to email.

## Appointments & Providers

- Many facilities are used for teaching and it can be overwhelming to have multiple people in the room. It is perfectly fine to request just the provider be present. Remember though that we are trying to train capable doctors and nurses and having them in the room helps them learn and understand about the unique needs of someone who has Spina Bifida. If you can tolerate it, it is helpful to have a learner in the visit sometimes.
- Usually at the end of an appointment you may see a social worker, nutritionist, etc. that will ask if there are any needs you may have. These are the correct people to discuss insurance, transportation issues, cost of food concerns, or special dietary needs.
- “Telling your story” - You will have to repeat and tell your story multiple times. It is part of healthcare and charting and requirements for insurance. Most physicians will want to hear you personally tell why you are there and what your concerns are.

## Sub Specialists

Neurosurgeon – Shunt malfunctions are less common in adults so you may not see a neurosurgeon in adult healthcare as much as you did in pediatric care. It has been our experience that if they are not connected to an MM clinic they will only want to meet you once and then will see you when there are worries or you are not feeling well.

Urologist – Usually will want to see patient every 6-12 months. Urologists have a better understanding of newer meds to take and also how to document the need for catheters.

Physical Medicine and Rehab- Specialists that are experts in maintaining physical movement and flexibility in the patient. They have additional training in bracing and equipment. Physical Medicine and Rehab specialists are good at evaluating problems and learn ways to adapt or problem solve for better movement. They are also very good at understanding how the body

ages and what type of things we need to think about in adulthood that can affect a person's ability to move. They often cross train and take care of both children and adults.

Orthopedist – Usually seen only if a problem is identified and surgery would help.

#### Communication

- If you are having trouble with a provider understanding why something has been ordered for you, go back to referring doctor and ask if they could follow up with communication on why it is needed.
- When calling be very clear with your questions and concerns.
- If you leave an appointment confused it might be the providers fault. If you stay confused it is your fault. Feel free to call the office for clarification. Do not wait until the next visit, as you might need to do something in the meantime. Make sure that when you call you tell the office you are confused. It will help them get your questions answered.
- If you leave with a “To Do” list from your provider – get it done before returning for the next appointment. If you are not sure how, or where to go to get things done, call the office.
- Who to call- Call both – your primary physician and your Spina Bifida specialists when you have a concern. Sometimes one may get back to you sooner, but it is always nice for all of your main providers to be on the same page. That way there are not duplicate orders. We don't want you to have the same tests multiple times.
- Develop a good relationship with the office staff. Be nice and respectful of their position and time. Show and express your appreciation.