

# INTHENews

## Taking the Temperature: A Discussion About Patient Care, Mental Health, and Providers During the COVID-19 Pandemic

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### BEST PRACTICE RECOMMENDATIONS

In response to the COVID-19 pandemic, many providers were notified in March about a move to telehealth. Families were called and notified of the change. While some families canceled appointments at first, most required multidisciplinary care as time went on (i.e., neurology, pulmonary care, endocrinology, orthopedic surgery, physical/occupational therapy, dietician services, social work, genetic counseling, and child life services on stand-by).

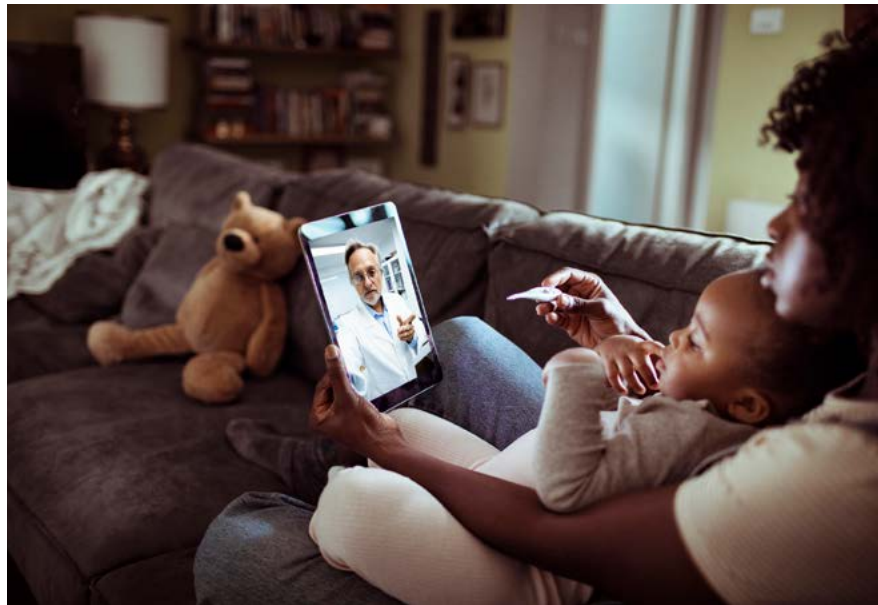
The direct clinical experiences of providers to remotely support the physical and mental health needs of patients with neuromuscular disease during the pandemic were used to develop the following best practice guidelines.

### PRACTICAL CONSIDERATIONS FOR SETTING UP AN INTERDISCIPLINARY TELEHEALTH CLINIC

While many patients with neuromuscular disease can be transitioned to telehealth for routine visits, urgent patients may still need to see a neurologist/neuromuscular or pulmonary specialist in person. Considerations for the transition to telehealth include:

#### Timing

One model for multidisciplinary care entails scheduling videoconferences with providers one after the other. This model has benefits and drawbacks:



- It is efficient and allows patients to see all of their providers/specialists
- If someone is running late, it creates a problem for scheduling

#### Communication

To overcome scheduling glitches, communication within the medical team is essential.

- All providers should be available to each other by cell phone and should exchange contact information
- Texting/calling regularly to notify team members about changes will help things run smoothly

#### Flexibility

Clinical team members and patients are dealing with various stressors. Flexibility is essential.

- There may be problems with the technology (e.g., cameras not working, etc.)
- Patients may struggle with the new format (e.g., children may not be amenable to the video calls, families may require interpretation services).

Some solutions include:

- Short calls, rescheduling, telephone calls instead of video
- Having an organized coordinator to keep the schedule on track
- Team members taking on additional roles, such as tech support for families

### Additional considerations

During the move to telehealth, a number of decisions need to be made:

- When to see patients
- How to bill for telehealth visits
  - Before the pandemic, visits with different providers were billed together
  - Because of billing platform and insurance limitations, billing for telehealth visits may need to be separated by provider
  - Insurance reimbursement for telephone vs. video calls is evolving and will require confirmation
- Who is scheduling the visits
  - Creating a master schedule early can help because some visits may require insurance approval, coordination between team members, etc.
  - Explaining to and obtaining consent from a patient for a telehealth visit takes a significantly longer time over the phone

### Provider experiences

Telehealth allows providers to gather new information and gain a new perspective about their patients. Through telehealth, they see the patients’:

- Homelife
- Physical environment
- Equipment
- Kitchen, food, and tools

### Practical considerations for reopening in-person clinics

After three months of offering almost exclusively telehealth appointments, offices are beginning to open for in-person visits. This timing is influenced by evolving insurance coverage for telephone calls, videoconferencing and in-person visits.

### Need to manage anxieties

- Some families prefer telehealth so that they do not have to venture outside or drive to the clinic
- Others want the social connection of in-person visits with their doctors
- Providers are experiencing burnout from the telemedicine videoconferences but will face different stressors when going back to in-person visits

### Logistics

- Safety is the most important priority
- Government guidelines for phasing-in will vary by state. One opening scheme — 25% capacity at first, then 50% capacity, then 100%
- Organizations need a plan
  - Communication is essential
  - Must implement a screening process — e.g., screening downstairs in the lobby, escort from the elevator to the exam room (no waiting area)
  - New patients will get priority for in-person visits because they will require physical evaluations
  - Clinical judgment will be used to determine which patients to see in person
  - Personal protective equipment (of different levels) is required when meeting in person

### SUPPORTING THE NEEDS OF PATIENTS AND FAMILIES DURING THE COVID-19 PANDEMIC

During this challenging time, it is important for providers to check in with all families. Check-in calls and videoconferencing show that the clinical team is still invested in their patients and that they still care. A goal of the provider is to identify and address concrete needs and needs related to COVID-19.

### Basic needs

Patients and caregivers are dealing with the loss of basic needs:

- Food insecurity
- Loss of jobs and employer-based insurance coverage
- Inability to pay bills

One suggestion is to create a resource-mapping document for patients. This living document should be regularly updated and include live links and numbers for local resources:

- Food banks
- Schools providing meals
- COVID-19 testing
- How to get utility bills, rent, mortgage paid
- Employers that are hiring
- Where to find mental health services and group therapy (free options, options with telehealth, etc.)
- How to get medical bills paid (i.e., charities and other resources)
- Hotels by the medical center for patients who test positive for the novel coronavirus and need to be seen in person

Consolidation of resources for staff can also be helpful:

- Childcare and other resources

## Emotional needs

Increases in depression have not been reported by participating clinicians, but patients and families are experiencing new stressors:

- Parents indicate more anxiety about keeping children safe from coronavirus exposure
- Spinraza patients/families are anxious because they have to come to the hospital for treatments
- Patients and caregivers face stress about not being able to separate work, home, rest space
- Parents are anxious about taking on new roles — homeschooling, etc.
- Patients are afraid because their doctors do not have all of the answers
- Patients and caregivers fear the possibility of the caregiver becoming ill
- Patients feel the loss of their freedom, security, normalcy/schedule, and experiences (e.g., graduation)

Asking specific questions can help to reveal and address anxiety:

- How are you spending your time? How are you feeling today? How are you sleeping? Did you go outside today? What are you doing for you? How are the telemedicine appointments going?
- Patients and caregivers are more receptive and inclined to share their anxiety when asked targeted questions
- Validating patient/caregiver feelings is especially important at this time
- Providers can use this conversation to share helpful resources
- Ending conversations with affirmations about how well the patients/family members are doing while managing these new circumstances can help to relieve some of their tension/stress

A major role for the provider is to focus on shelter-in-place and protection, in order to preempt difficult, stress-inducing scenarios such as a caregiver becoming ill. If this does occur, providers can help by:

- Following CDC guidelines for medical care
- Exploring isolation options
- Encouraging mask wearing, handwashing, and other safety protocols (often young patients cannot be separated from a sick caregiver)
- Identifying resources (e.g., people who can help)
- Supporting families in their anxiety

## Socialization and work needs

Some patients feel isolated because of school cancellations, social distancing requirements, etc., while others lived a solitary life prior to the pandemic because of the difficulties and stigma related to their condition. The little socialization they may have had is gone, so checking in is so important. Providers can help by:

- Recommending online groups
- Giving suggestions to add structure to the day
- Providing suggestions for parents whose roles are changing, i.e., acting as parents, school teachers, caregivers
- Encouraging patients to take their normal activities outside

Clinicians may be asked to write letters to employers to enable patients/family members to work from home or be placed on furlough for their safety and security.

## SUPPORTING THE NEEDS OF PROVIDERS DURING THE COVID-19 PANDEMIC

Providers also are experiencing fatigue from the current circumstances. They are dealing with:

- Anxiety and physical fatigue
- Balancing personal vs. professional while taking care of patients
- COVID fatigue, video fatigue
- Missing the interaction with the children they care for
- New roles — planning unorthodox memorial services.
- Home challenges — maintaining work/home life

It is important for team members to be supportive of each other

- One suggestion is to put out an internal newsletter providing good news and praising the work/efforts of team members
- It is also helpful for the team to check in with each other before and after each multidisciplinary telehealth clinic to share how they are doing

## Strategies for coping through the pandemic

- Coping with increased screen time
  - Be willing to say no to another screen request
  - Prioritize time in the day without a screen, even if it is difficult
  - Determine the best method to connect — phone, video, message, email
  - Create simple short rituals to begin or end your meeting or screen time
- Sustaining well-being and resilience
  - Normalize your experience and your feelings, especially the exhaustion or moral distress
  - Grieve what you need to grieve
  - Give self-compassion through self check-ins and limiting your “shoulds”
  - Simplify expectations and plans
  - Be grateful for ordinary things
  - Do one thing you love each day
  - Play through something tangible (gardening, baking bread, building with Legos, playing with kids)
  - Maintain social connections (call family, send a message, create a quarantine mini-group).