Communication

Best practice recommendations for giving the diagnosis of cerebral palsy

1 Conveying the diagnosis of childhood disability to a parent is complex, but it is important that it is done well. When bad news is given well, hope can be conveyed, parent-child bonding can be facilitated, and satisfaction with the healthcare system is fostered.

Strong Recommendation For
based on high quality evidence for infant and parent outcomes

2 A diagnosis should be given as early as possible to:

- Maximise the child's potential from early intervention.
- To reduce parental stress and anger from diagnostic uncertainty.

Strong Recommendation For
based on high quality evidence for infant and parent outcomes

3 Diagnosis should not be delayed or withheld to protect parent's feelings.

Strong Recommendation AGAINST
based on high quality evidence for infant and parent outcomes

4 Mental preparation, factual preparation and environmental preparation is necessary before giving a diagnosis. A private, quiet room is recommended where both parents (where relevant) and the infant are invited to be present. [SPIKES STEP 1]

Strong Recommendation FOR
based on high quality evidence for parent outcomes and
low quality evidence for reducing stress in clinicians

5 Gain an understanding of the parent's current knowledge before giving a diagnosis. [SPIKES STEP 2][1]

Strong Recommendation For
based on high quality evidence for parent outcomes

6 Ask and invite questions. [SPIKES STEP 3][1]

Strong Recommendation For
based on high quality evidence for parent outcomes

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7 Provide evidence-based facts. Answer questions honestly and using jargon-free language. Provide written information to allow later processing and information sharing with other family members (refer to Supplementary Table 2). [SPIKES STEP 4] [1]

Over a series of conversations, plan to discuss:

- Definition, prevalence, types, prognosis
- Cure
- Causes
- Prevention of complications
- Early intervention
- Medications
- Expected outcomes of treatment
- Caregiving stress
- Behaviour Management
- Adaptive Equipment
- Parent Support and Impact on the Family
- Future planning and life expectancy
- Reputable Sources of Information

Strong Recommendation For
based on high quality evidence for infant and parent outcomes

8 Respond emphatically to emotions. [SPIKES STEP 5][1]

Strong Recommendation For
based on high quality evidence for parent outcomes

9 Make a follow-up appointment to continue the diagnostic discussions. Arrange a treatment plan including early intervention and parent support [SPIKES STEP 6][1]

Strong Recommendation For
based on high quality evidence for infant and parent outcomes

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The Six Steps of SPIKES to Communicate a Diagnosis[1]

1 S - SETTING UP THE INTERVIEW

Take time to prepare

- use a quiet, private office[2]
- allow adequate time[3]
- schedule at least two information sharing sessions [4]
- Invite both parents and infants to be present[5]
- Prepare for difficult questions and different responses from each parent[6]
- use mental rehearsal to prepare for difficult questions[1]
- Prepare positive information about child strengths and hope for their future[5]

2 P - ASSESSING THE FAMILY'S PERCEPTION

Ask don't tell

- Use open-ended questions to gain a picture of what the parent already understands[1]
- Tailor information on parent's answers and individual child.[1]
- Reframe misunderstandings[1]
- Provide honest, transparent and specific information about future prognosis[7]

3 I – OBTAINING THE FAMILY'S INVITATION

Take time to respond to questions

- Invite questions[1]
- Communicate your willingness to listen the parents' questions both now and in the future.[1]
- Answer questions openly and honestly[7]

4 K – PROVIDE KNOWLEDGE AND INFORMATION

Warn that there is bad news ahead

- Use simple, direct, jargon-free language[7]
- Use a hopeful, empathic and supportive tone[5]
- Be clear and certain.[6]
- Provide written information to allow later absorption and communication of the news to other family members and friends.[8]

5 E— ADDRESSING THE FAMILY'S EMOTIONS

Respond empathically to emotions.

- Observe and name the emotions[1]
- Encourage and validate emotions[9]
- Invite discussion about their feelings[5]
- Offer assistance to tell others[4]

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6 S – STRATEGY and SUMMARY

- Check with the family to see if they are ready to discuss treatment planning[1]
- Involve the family in treatment planning[1]
- End sessions with something practical and helpful that parents can do[6]
- Arrange next review and debriefing
- Recommend parent-to-parent and family support[7]
- Appoint a key worker for service navigation[2]
- Arrange early intervention[3]

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Understanding the parent's perspectives of early diagnosis of cerebral palsy

The Bad News Response Model

Parents can respond to bad news by:
(a) Watchful Waiting,
(b) Active Change,
(c) Acceptance, and
(d) Nonresponding i.e. protective denial.

Clinicians should support parents to shift from "watchful waiting" to "active change" and "acceptance".

Parents require detailed information about the diagnosis, treatments, prognosis and supports.

The model redirects the focus from the clinician's emotions to the goal of fostering long-term adaptive parental responses to the bad news. The model also provides real-time feedback about whether the mode of news delivery was effective or not, and thus allowing re-communication.[1]

Active Change Response

- Seeks to bring about engaged parental responses towards addressing their bad news
- Clinicians need to teach and show parents how to help.

Active Change includes three types of behaviour on the part of parents:

(a) information seeking
(b) taking steps to prevent deterioration from the condition; and
(c) instigating treatment that brings about improvements in their child's development.

- Provide ongoing information, to lower anxiety.
- Provide information about a range of evidence-based treatments and where to access these treatments.
- Foster parental problem-solving and raising awareness about their child's needs, so that they can coordinate and plan their child's care.
- Parent education and coaching in how to parent their child is often required[1].

1. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES – A sixstep protocol for delivering bad news: application to the patient with cancer. Oncologist 2000; 5: 302–11.

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Acceptance response

The “Acceptance” response to bad news is where parents come to accept their circumstances and are able to create meaning in their loss, “reduce their dread over what lies ahead”, and seek support in order to cope .

Acceptance involves two types of behaviour on the part of parents:

(i) information sharing about their story with others, and
(ii) accommodation, which actively involves incorporating their child’s diagnosis into their family life, by reordering priorities and adjusting to a new future.

As we build relationships with parents over time, it is important to acknowledge and listen to their expertise.

Parents want equal and cooperative relationships with clinicians.

Hear and understand what is important to families, empowering them by discussing openly their hopes and goals, always referring to the child by name and avoiding labelling them as abnormal or by their diagnosis.

Clinicians also need to stay up to date regarding prevalence of disability and common comorbidities so that they can provide accurate and balanced information that is personalised to each family[1].

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Types of Information and Knowledge Needed by Parents

1 DIAGNOSIS

DEFINITION

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.[1]

PREVALENCE

Cerebral palsy is the most common cause of physical disability in childhood. Link: What is cerebral palsy?

TYPES

Motor Types, Topography and Classifications:

Four motor types exist but may emerge and change during the first two years of life:

(1) Spasticity. Spasticity is categorised topographically as (i) unilateral (hemiplegia) 38% and (ii) bilateral (including diplegia lower limbs affected more than upper limbs) 37% and quadriplegia (all 4 limbs and trunk affected) 24%[2]

(2) Dyskinesia including dystonia and athetosis;

(3) Ataxia; and

(4) Hypotonia.

There may be more than one motor disorder. A combination of spasticity and dystonia is common[2]. In childhood, several objective classification tools exist to classify the child's function, including the Gross Motor Function Classification System, (GMFCS- E&R)[3] and MACS Manual Ability Classification Systems[4].

EARLY DIAGNOSIS

Cerebral palsy or high risk of cerebral palsy can be accurately diagnosed early, in many cases under 6 months corrected age. High quality evidence indicates the combination of medical history and standardised tools should be used to predict risk. Before 5 months corrected age, neuroimaging (MRI), the Hammersmith Infant Neurological Examination (HINE) and Prechtl's General Movements Assessment (GMs) are the most predictive tools. After 5 months corrected age, MRI and the HINE are most predictive of risk for cerebral palsy. [5] When standardised assessments indicating cerebral palsy is suspected, the interim clinical diagnosis of "high risk" of cerebral palsy should be given. Essential criterion of motor dysfunction and at least one of the additional criteria of abnormal neuroimaging or clinical history indicating risk for cerebral palsy are required. This should be followed by referral for cerebral palsy specific early intervention and parent or carer support. Ongoing monitoring to assist in forming the diagnostic picture is recommended.[5]

Neurological Test: A Hammersmith Infant Neurological Evaluation (HINE) score below 57 at 3 months is 96% predictive of cerebral palsy. A HINE score below 40 at 3 months never occurs in children with normal outcomes.[6,7]

Motor Test: An abnormal General Movements Assessment score of "absent fidgety movements" at 12–20 weeks corrected age is 95-98% predictive of cerebral palsy.[8]

Link: https://www.cerebralpalsy.org.au/services/for-children/newly-diagnosed/

CURE

The complete causal path to cerebral palsy is unclear in 80% cases, but clinical risk factors are often identifiable and include risks prior to conception, during pregnancy, around the time of birth and postneonatally.[10]

PROGNOSIS

Diagnosticians should answer questions about prognosis as accurately and clearly as possibly, whilst maintaining a positive outlook. Where appropriate, the use of accurate prognostic facts such as "most children with cerebral palsy will walk" [11] can create a positive picture of a child with cerebral palsy for families.

0-2 years old: In children under 2 years of age motor severity is most accurately predicted using the HINE[12,13],and MRI.[14] Caution should be taken when giving prognostic information about motor prognosis under the age of 2 years, as voluntary movement, myelination and brain growth is still developing.

Over 2 years old: In children over 2 years of age, the severity of gross motor function is most reliably classified using the GMFCS.[3]

Link: Gross Motor Function Classification System (GMFCS – E& R)

PREVENTION OF COMPLICATIONS

The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.[1]

- 3 in 4 experience chronic pain;
- 1 in 2 have an intellectual disability;
- 1 in 3 cannot walk;
- 1 in 3 have hip displacement;
- 1 in 4 cannot talk;
- 1 in 4 have epilepsy;
- 1 in 4 have a behaviour disorder;
- 1 in 4 have bladder control problems;
- 1 in 5 have a sleep disorder;
- 1 in 5 dribble;
- 1 in 10 are blind;
- 1 in 15 are tube fed;
- and 1 in 25 are deaf.[15]

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Co-occurring impairments are strongly linked to the severity of motor impairment. Medical investigations for associated impairments are always indicated in cerebral palsy. There are evidenced based recommendations and expert opinion care pathways for the medical and surgical management of children with cerebral palsy.[16] Early management of associated impairments and timely evidenced based interventions can improve outcomes [17]

HIPS: Hip displacement occurs in 1 in 3 children with cerebral palsy. Children with non-ambulant bilateral cerebral palsy are most at risk. Hip dislocation can be prevented through early surveillance and management.[17]
Link: Australian Hip Surveillance Guidelines

PAIN: 3 in 4 children with cerebral palsy have chronic pain. Detailed pain assessment and management is important but often overlooked.[18]

SLEEP: 1 in 5 children with cerebral palsy have sleep problems, specialist assessments and early treatment are recommended.[19] Pain, breathing problems, vision impairment and epilepsy can affect sleep.[20]

Link: American Academy for Cerebral Palsy and Developmental Medicine Care Pathways

2 TREATMENT

TREATMENT PLAN

Goal based approach: Best practice rehabilitation and psychological evidence supports treatment planning based on child and family goals. Active involvement of the parents in all decision making and treatment goal setting, considering family values, expectations and preferences achieves better outcomes for children and parents[21].

EARLY INTERVENTIONS

Cerebral palsy specific interventions exist, and are increasingly tailored to a specific type of cerebral palsy. Categorisation by typography of unilateral or bilateral is important to guide intervention. For example, early bimanual and constraint-induced movement therapy (CIMT) are recommended for unilateral cerebral palsy[22]. Emerging evidence is supporting early task-specific, child-initiated, and enriched environmental interventions for motor and cognitive gains[21]. Aims of optimising motor, cognitive, and communication outcomes for children, prevention of secondary impairments and promoting caregiver coping and mental health should all be considered in treatment plans[22].

MEDICATIONS

Pharmacology can play a role for people with cerebral palsy in promoting health and secondary preventions. Effective pharmacologic interventions include the management of symptoms such as epilepsy, pain, tone management (baclofen, intrathecal baclofen (diazepam, botulinum toxin type A) and bone density (bisphosphonates).[23]

LEISURE

Children with cerebral palsy are able to be actively involved in a wide range of leisure activities, and experience a high level of enjoyment. Data suggests however, that they participate less in physically active leisure compared with peers, and that participation reduces over time. Parents of children with cerebral palsy rank participation as their second most important research priority.[26]

EXPECTED OUTCOMES

Communication regarding interventions and expected outcomes needs to be honest, holistic, family-centred and mindful of the ethical complexities in supporting and responding to families' hopes, goals and requests for treatments[27]. Parents are challenged from choosing a wide variety of therapy options, many of which have uncertain effects with some proven to be ineffective[23]. To enable discussion on expected outcomes of interventions, a defined goal, including its relative level of the International Classification of Functioning, Disability and Health (ICF) needs to be established[28].

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3 EQUIPMENT

ASSISTIVE DEVICES AND EQUIPMENT

Most children with cerebral will have some difficulty with functional independence. Assistive devices (such as for walking, communication) and equipment (such as wheeled mobility, seating and pressure mattresses) can help with independence, conserving energy and time, improving safety, and reducing your caregiving burden (such as shower chairs, toilet supports and lifting devices).

FINANCIAL SUPPORT

Understanding the complexities of funding systems for children with a disability can be challenging for health professionals and stressful and time consuming for parents.

4 DAILY CAREGIVING

BURDEN OF CARE GIVING

Parents and carers may experience an increased parenting burden, including complex care responsibilities, social isolation or financial hardship as a result of their child's disability[29]. Parent and carer wellbeing can impact on child outcomes[29].

BEHAVIOUR MANAGEMENT

1 in 4 children with cerebral palsy have a behaviour disorder. Rates of behaviour disorders are higher in children with an intellectual impairment, in children with severe pain and in children with lower severity levels of cerebral palsy. Parent education is recommended in behaviour management. The positive parenting programme, (Triple P) can be effective in reducing disruptive behaviours of children with developmental disabilities[30].

Link: Triple P Positive Parenting Program

5 FUTURE

DEVELOPMENTAL TRAJECTORY OF GROSS MOTOR SKILLS

Gross Motor curves exist that describe motor potential and the point at which motor development plateaus, which can inform the development of a realistic treatment plan. Children with ambulant cerebral palsy achieve 90% of their gross motor development potential by age 5 years, and children with non-ambulant reach 90% of their gross motor development by age 3.5 years. Before a child plateaus, focusing on active skill development is important, after the child plateaus it is important to prescribe compensatory equipment (such as a wheelchair) to ensure the child is fully included.

ADOLESCENCE

Children with cerebral palsy can show signs of ageing and physical decline in their adolescent years.[32]

ADULTHOOD

Compared with able bodied peers, adults with cerebral palsy are less likely live independently, have intimate relationships or maintain gainful employment.[33] Adults with cerebral palsy may require assistance with employment initiatives, advocacy needs to continue to counter discrimination, appropriate accommodation, transport, equipment and home modifications.[34]

EDUCATION

Children with disability have the same education rights as all other children. Educational rights are protected by law. Parents are encouraged to explore options available for their child. Access to appropriate support and adaptations to allow for inclusion in education should be provided.

Link: Raising Children Network Education Rights in Australia

LIFE EXPECTANCY

Cerebral palsy is permanent and lifelong. Life expectancy is almost always normal. Life expectancy decreases with increasing intellectual disability, epilepsy and increasing physical disability. There have been significant improvements in survival of children with severe cerebral palsy in recent decades[36=].

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6 HEALTHCARE PLANS

RECOMMENDED REVIEWS

Surveillance: Health Surveillance programs aimed at identifying onset of associated impairments and referring to timely interventions to prevent complications exist. Early management and evidenced based interventions can improve outcomes. Examples are CPUP in Sweden, CP CheckUp in Australia and hip surveillance programs.

7 SUPPORT

CEREBRAL PALSY STRATEGY

The Australian and New Zealand Cerebral Palsy Strategy reflects a united voice informed by people with cerebral palsy, their families, professionals and researchers across Australia and New Zealand.
www.cerebralpalsystrategy.com.au

PARENT TO PARENT SUPPORT

Parents indicate parent-to-parent and family support facilitates long term coping[37].
Link: Parent Tip Sheet Parent2Parent CanChild

COMMUNITY SUPPORT

Informal and formal community supports[37] can play important roles in active change and acceptance responses.

LEGISLATION, ADVOCACY & FINANCIAL

Advocacy is of utmost significance in a child's support system[37]. Anti-discrimination legislation exists to ensure people with a disability are not discriminated against.
Link: Raising Children Network

8 FAMILY SUPPORT

SIBLINGS

The impact of cerebral palsy on the whole family is complex and challenging. Siblings may require their own individual support.
Links and Books:
Raising Children Network Siblings
CP NOW Toolkit - Impact on CP Diagnosis on Family and Siblings
Views from our Shoes: Growing up with a Brother or Sister with Special Needs, Donald J. Meyer

COPING

The process of parental acceptance of a cerebral palsy diagnosis, grieving, coping and resiliency is ongoing, cyclical and requires a continuum of supports from diagnosticians. Parent child attachment and caregiver mental health interventions such as acceptance and commitment therapy are helpful interventions to assist with caregiver coping.
Books:
Uncommon Fathers: Reflections on Raising a child with a disability. Donald J Meyer.
Married with Special needs children: A couples guide to Keeping connected, Laura Marshak and Fran Prezant.

PARENT MENTAL HEALTH AND WELLBEING

Mothers of a child with a disability report high rates of distress, anxiety, depressions and suicidality[38]. 1 in 4 parents of children with CP have very high stress. Mothers report the perceived need for professional mental health support, and support is most wanted around the time of diagnosis[38].
Link: Parent Wellbeing Resource

PARENT INFORMATION

Australian and New Zealand Cerebral Palsy Strategy Collaboration
www.cerebralpalsystrategy.com.au
Cerebralpalsy.org.au
Canchild.ca
Cpnowfoundation.org
Cpdailyliving.com
Cdc.gov
Neurodevnet.ca
Ucp.org
Scope.org.uk
Cpsn.org.au
Cpfamilynetwork.org
Reachingforthestars
yourcpf.org/
Aacpdm.org.
Cerebralpalsy.org.uk
Ausacpdm.org.au.

9 EXPLANATIONS TO OTHERS

EXPLAINING THE DIAGNOSIS

"Talking to family and friends, or showing them resources about your child's disability can help them understand and support you. But what you talk about, how much you say and who you talk to is up to you.".
Links: Talking to Others About Your Child and CP.
Raising Children Network - Talking About Disability
CP NOW Toolkit: Impact on CP Diagnosis on Family and Siblings
Children's Books:
What Are Your Superpowers? By Marget Wincent ISBN 9781540897817;
Jessica's Box By Peter Carnavas ISBN 9781921928574;
My Friend Suhana. By Shaila Abdullah and Aanyah Abdullah ISBN 9781615992119.

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Communication

Common questions asked by parents of children with cerebral palsy

PARENT QUESTIONS MOTOR TYPE/ PROGNOSIS	ANSWERS: WHAT CAN WE SAY/ WHAT CAN WE DO NOW ?
Case 1: **12-months old, Spastic hemiplegia, GMFCS I, HINE at 6-months 68.5, HINE at 12-months 67.5**	
Does she have a problem with high tone in her right leg?	*Today she has a "catch", or resistance to movement, in her calf muscle, which means she does have mild spasticity in this muscle.*
Can spasticity and contractures get worse when she is older?	*As she grows, spasticity might develop in other muscle groups. For children who have mild spastic hemiplegia, it is not unusual for contractures to develop over childhood, but we do not know when they will develop. Most often it is during growth spurts, when bones are growing faster than the muscles.*
Do children who have a similar type of CP also have a limp?	*Children with mild hemiplegia can have changes to their muscles and joints over time, which can go on to cause a limp. We do not know if and when this is likely to develop for your daughter. We recommend regular checks of her muscles and developmental skills, to understand her development and the best course of treatment.*
Will she be able to run when she grows up?	*Right now, she is developing her gross motor skills on par with children her age. This is good news. We also know that motor tests often don't show difficulty with more intricate skills until later on. We do predict that she is going to be able to run, but she might have difficulty with some higher-level skill such as hopping and skipping. There are therapy interventions which can help to target developing these higher-level skills.*
Case 2: **4-months old , Type and Typography Unknown, GMFCS too young to determine, HINE at 3-months 47**	
Can the results of the HINE change over time and move into the optimal range?	*Usually the HINE improves a little bit with time as children get older. For each age, there is an optimal score range. Multiple tests of the HINE over time give us a better understanding of his brain function.*
His MRI is clear, does this mean he will be OK?	*You are right, his MRI didn't show any clear abnormalities. In some cases, children with a clear MRI can still go on to have developmental problems, for example 10% of children with CP have a normal MRI, which means we need to keep monitoring him. This is especially important because of his history of Encephalopathy and his HINE score. What we recommend is doing a repeat HINE in 1 month and see what that shows us. Is there anyone else you would like to be at that appointment with you?*
Some days his hands are fisting, on other days they aren't. Last week you felt tone in his legs, and this week it isn't there. What does that mean?	*Your observations are right. He does have changing tone in his arms and legs – we call this variable movement "dystonia". The fluctuations are involuntary. We will monitor his dystonia closely over time to see if we need to add any new treatments or change treatment plans.*

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Cerebral Palsy ALLIANCE

THE UNIVERSITY OF SYDNEY

AusCP-CTN Australasian Cerebral Palsy Clinical Trials Network CENTRE FOR RESEARCH EXCELLENCE

Communication

PARENT QUESTIONS MOTOR TYPE/ PROGNOSIS	ANSWERS: WHAT CAN WE SAY/ WHAT CAN WE DO NOW ?
Case 3: 9-months old, (Emerging) , Spastic diplegia, GMFCS Too young to determine, HINE at 3-months 59	
I have noticed he stands on his toes and holds his knees stiffly. Is the stiffness in his legs of concern?	*Stiffness in his legs is something we are concerned about. Today, he wasn't showing what we call a spastic catch. However, often muscle spasticity (or over-activity) doesn't present fully until around 12 months of age. This is because the insulation of the nerves, called myelination, is still emerging. We recommend checking his muscles over time. He is starting to show some early control of his legs, which can help counterbalance involuntary muscle stiffness. For now, keep up the therapy focussed on learning skilled movement and control of movement.*
I think his hands are OK, they don't seem to get stiff– do you?	*I agree, it seems like he has more stiffness in his legs than his arms when he is moving and playing. In my assessments, today I haven't felt any spastic catches in any muscles. We will keep monitoring him over time, and keep a close eye on how his movements and skills are developing. For now, keep giving him lots of opportunities to practice developing his hand skills.*
Some days his hands are fisting, on other days they aren't. Last week you felt tone in his legs, and this week it isn't there. What does that mean?	*Your observations are right. He does have changing tone in his arms and legs – we call this variable movement "dystonia". The fluctuations are involuntary. We will monitor his dystonia closely over time to see if we need to add any new treatments or change treatments.*
Case 4: 11-months old, Dyskinetic, Quadriplegia, Predicted to be GMFCS V, HINE at 6-months 22	
What does a low HINE score mean?	*Stiffness in his legs is something we are concerned about. Today, he wasn't showing what we call a spastic catch. However, often muscle spasticity (or over-activity) doesn't present fully until around 12 months of age. This is because the insulation of the nerves, called myelination, is still emerging. We recommend checking his muscles over time. He is starting to show some early control of his legs, which can help counterbalance involuntary muscle stiffness. For now, keep up the therapy focussed on learning skilled movement and control of movement.*
What is the likelihood that he will walk?	*I agree, it seems like he has more stiffness in his legs than his arms when he is moving and playing. In my assessments, today I haven't felt any spastic catches in any muscles. We will keep monitoring him over time, and keep a close eye on how his movements and skills are developing. For now, keep giving him lots of opportunities to practice developing his hand skills.*

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Communication

Communicating difficult news via telehealth

Communicating a cerebral palsy diagnosis to parents should always be delivered with sensitivity and be supported by facts and practical resources, as outlined in Communication Fact Sheets 1-5. These considerations are even more important if the diagnosis has to be delivered via telehealth.

Telehealth creates a virtual barrier between practitioner and patients/parents and this needs to be taken into consideration when delivering sensitive news.

To assist the parents in receiving and processing the news, consider the following:

- ensure that you have allowed adequate time for the telehealth appointment so that you do not risk being cut off or interrupted;
- ensure that disruption, distractions and external noise are kept to a minimum;
- be aware that the parents are likely to be on the call from their own home with the possible distractions of the patient and/ or other children demanding attention;
- ensure that you have prepared for the appointment and have all records and reference material immediately to hand to allow you to best respond to parents' queries;
- pre-preparing follow up communication and links that can either be sent immediately after the telehealth appointment so that the parents experience continued and reinforced support; and
- setting a follow up tele-health appointment either by yourself or a support worker to assist parents - noting that they will have a lot more questions in the days following diagnosis than they had during the initial appointment.

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