

# **Module 3: Developing an Effective Care Plan**

## Module 3: Developing an Effective Care Plan

### Learning Objectives

- Develop and manage a comprehensive care plan in partnership with the child or youth, his or her family, and others involved in the care team (including specialists and community partners).
- Describe communication strategies that can be used when developing a care plan with children and their families that demonstrate respect for varied cultural and linguistic beliefs and practices.

### Pretest

1. All children in a pediatric practice should have a care plan created to guide their treatments. True or false?
2. A care plan should not only outline a child's medical treatment but also include an assessment of which of the following issues?
  - a. The child's and family's strengths and needs.
  - b. Social and developmental issues.
  - c. The child's educational needs.
  - d. Financial concerns.
  - e. All of the above.
3. Research suggests that failure to plan and coordinate care may be common in many primary care practices and can disrupt continuity of care. True or false?
4. The care planning process can include reaching out to specialists through the use of any available electronic health record system, e-mail system, or text-messaging application. True or false?

### Overview

The American Academy of Pediatrics states that “care plans are an essential part of the medical home.”<sup>1</sup> They include all pertinent current and historical, medical, and social aspects of a child's and family's needs. They also contain information about interventions; each partner involved in the patient's care; contact information for specialists, community partners, and others involved in the child's care; and an action plan that is created in partnership with the patient and his family. According to the American Academy of Pediatrics policy statement *Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems*,

[c]are planning includes the use of an “actionable” care plan with assigned tasks/roles, a care plan document, an emergency information form, and/or a medical summary, including past medical history and salient specialist information. These care plans are developed and implemented with input from members of the team caring for a child, including community partners, educational specialists, primary care providers, dental providers, medical subspecialists and surgical specialists, and, most importantly, the family and patient themselves.<sup>2</sup>

Note that care planning happens over time and is not a “one and done” approach to patient care. Nor is it necessarily required for all children. A child who comes into the office with an acute ear infection, for instance, but who is otherwise healthy, might receive an after-visit summary with patient instructions and have no need for a care plan, but many other children require a care plan.

For children who would benefit from a care plan, it becomes the central repository in their charts and can be incorporated into most electronic health record (EHR) systems. This plan is managed by the medical home but informed by anyone involved in care of the child. As the following case study illustrates, the phases of care planning include:

- Assessing which child needs a care plan
- Ensuring the family is central to creation of the care plan
- Ensuring the care plan is maintained, updated, and shared with all appropriate parties, including specialists and community partners

The care planning process starts with an understanding of the child’s and family’s needs and strengths. This can happen only when the medical home team develops a strong, trusting relationship with the family. Once that takes shape, the team can “perform a comprehensive assessment of strengths, needs and gaps, and address interrelated medical, social, developmental, psychological, behavioral, educational, environmental and family financial concerns.”<sup>3</sup>

Results of that assessment can be used to create partnerships among medical home team members, the child and family, specialists, and community service professionals (eg, mental health, educational system) who may be contributing to the child’s care. As these partners work together, they develop shared goals and outcomes for the child in a coordinated effort.

The next step is creating a care plan and putting it into action. Care plans are especially valuable for children with chronic conditions that should be carefully monitored. Care plans are also valuable for children when they face emergency situations allowing rapid exchange of salient information; the care plan should outline a set of specific actions to be taken in such circumstances.<sup>3</sup> The care plan also helps summarize the child’s history, ensuring families do not have to repeat all details of their child’s past medical history in each clinical and/or community encounter with their child. Finally, it fosters shared decision making and provides families with a memorialized summary and understanding of who is responsible for what aspects of their child’s care. Links to sample care plan templates can be found under “Resources” at the end of this module.

The case study that follows is **not** designed to provide residents with the full clinical picture of a patient but to illustrate how patient- and family-centered medical home concepts can be put into action in everyday medical practice.

## **Case Study**

### *Visit 1: Explaining the Care Planning Process*

Jennifer Marconi, aged 7, was recently diagnosed with type 1 diabetes. She and her parents have already met with an endocrinologist and received basic education about the condition and how to manage it (with insulin injections, diet, physical activity, and blood glucose monitoring). The family is now in for their first visit with her pediatrician, since meeting with the endocrinologist.

At the initial post-diagnosis visit, one of the pediatrician's first priorities is reinforcing the education Jennifer already received from the endocrinologist. The next task is to improve coordination of her care. Research suggests that failure to coordinate care is common in primary care practices and can have serious consequences.<sup>4</sup> For instance, communication between primary care physicians and specialists is often inadequate, with too little information changing hands to ensure the best continuity of care. Part of the solution is to develop a care plan that is shared among all caregivers and providers to optimize care coordination.

It is not enough to share information between pediatricians and specialists. A child and her family need to be involved in the care planning process.

During the visit, the pediatrician shows the family a sample care plan and explains that it is more than just a summary of the child's medical history and treatment plan. It also includes shared strategies, what the team and family hope to accomplish over time, and a list of agreed-upon tasks and interventions. The care plan addresses a child's needs, not just clinical ones but also developmental, educational, social, and financial ones, and includes durable medical equipment, if necessary or appropriate, and insurance information. It also contains the names and phone numbers of specialists, equipment suppliers, and pharmacies, as well as information about how to obtain lancets and glucometers. Finally, the care plan allows a family to have a summary of salient information for other caregivers and schools. The pediatrician asks the family open-ended questions to solicit their feedback about the care plan and to gauge their understanding of its use and utility and also asks if there are other sections of the care plan that aren't included that the family would like to add.

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Potential Care Plan Components

- Diagnosis
- Provider contact information
- Presenting problems
- Patient and family strengths
- Patient challenges
- Prior surgeries and/or procedures
- Recent laboratory and other diagnostic studies
- Assistive technology
- Patient and family goals

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Because of this discussion, the family sees the value of a care plan in helping manage Jennifer's blood glucose levels, nutritional needs, and insulin regimen—as well as numerous non-medical concerns. The Marconi family is pleased that they have a say in how Jennifer's treatment will unfold and agree to schedule a second office visit to work with the medical home team to complete the care plan in full.

### *Visit 2: Designing the Individualized Care Plan*

During a next visit, a nurse in the practice and the family begin filling out the necessary sections of a care plan template together. This includes documenting emergency contact information, diagnoses, allergies, medications and their dosages, the names and contact details for her specialist, and school name and contacts. Equally important, the nurse discusses what Jennifer and her parents hope to accomplish from clinical, educational, and psychosocial perspectives. They have two primary goals, which are documented in the care plan, which are management of type 1 diabetes and improved communication, collaboration, and coordination of care among Jennifer, her family, providers, and her school. While many practices work on the entire care plan together with the family while they are in the office, others will have the child and family fill out some portion of the form at home, accessing it through an online patient portal and giving input electronically.

Here are some clinical issues the nurse discusses with the family. Once discussed, they are incorporated into the care plan.

- Is Jennifer comfortable self-monitoring blood glucose?
- Does she need more training on the procedure?
- What's her hemoglobin A1c goal?
- Is Jennifer comfortable with her medication regimen? Does Jennifer need more education on how to administer insulin?
- Does she understand the carbohydrate dose calculation to determine the amount of insulin to inject?
- Do she and her family know who to call for the various aspects of her care?
- Does the family know what to do when they run out of supplies?
- Do she and her family know what signs and symptoms of hypoglycemia to watch for?

This nurse also discusses with the Marconi family their cultural values and norms and how they may affect Jennifer's course of treatment. For example, they spend time discussing how Jennifer can navigate social family gatherings where traditional foods are served, which tend to be high in carbohydrates, in order to maintain appropriate blood sugar levels. These strategies are documented in Jennifer's care plan.

The Marconis are concerned with how diabetes and its management will affect Jennifer when she is in school, such as how insulin therapy will be administered while she is in class. Similarly, they want to know how her physical education class will affect her insulin and nutritional needs and what role her teacher will have to take on in case of a hypoglycemic incident. Once the medical home, family, and school work out a plan, these details will be documented in the care plan as well and shared with all involved parties.

They also express concern that their daughter's special needs may be imposing an unreasonable burden on the school's staff. It is important for the family to understand that Jennifer's school has a legal obligation to accommodate her needs. The nurse explains Section 504 of the Rehabilitation Act, the federal law prohibiting discrimination against people with disabilities. That law requires schools to take steps to ensure that students with diabetes are medically safe, have access to the same educational opportunities as other children, and are treated fairly.<sup>5</sup> As the US Department of Health and Human Resources Office of Civil Rights explains,

Section 504 forbids organizations and employers from excluding or denying individuals with disabilities an equal opportunity to receive program benefits and services. It defines the rights of individuals with disabilities to participate in, and have access to, program benefits and services.... People who have a history of, or who are regarded as having a physical or mental impairment that substantially limits one or more major life activities, are also covered.... Some examples of impairments which may substantially limit major life activities, even with the help of medication or aids/devices, are the following: AIDS, alcoholism, blindness or visual impairment, cancer, deafness or hearing impairment, diabetes, drug addiction, heart disease, and mental illness.<sup>6</sup>

Even the most optimal care plan would be of limited value if it were not readily available to every member of the care team who would benefit from it, including the family. Care plans need to be

accessible, retrievable, and available. To accomplish that goal, at end of this particular visit, a medical assistant inputs Jennifer's care plan into her EHR. One option is to scan the document in as a pdf, though many EHR systems contain a template that is populated with such information during a visit or encounter. The practice also makes the care plan available to the Marconi family by putting it up on its patient portal. The family can access this portal after the visit from any location with Internet access. Lastly, because the family signed a release of records form, the medical assistant sends a secure e-mail to the school nurse containing the care plan to foster care coordination and co-management. Co-management involves enhanced communication and sharing of care among families and professionals. Chronic condition management tools, such as co-management letters and care-sharing agreements, support these communications.<sup>7</sup>

Following the visit, the nurse also reaches out to Jennifer's endocrinologist to coordinate care. Care planning includes the development of a strong relationship with Jennifer's endocrinologist. Some patients are comfortable managing communication between their primary care physician and specialists; others are not. A conversation with the Marconis revealed that they prefer the medical home team take the lead on this, and the nurse follows through to make sure there is good two-way communication with the endocrinologist staff. She reaches out personally to introduce herself by phone and sends a secure, encrypted HIPAA (Health Insurance Portability and Accountability Act)-compliant e-mail to the endocrinologist's medical assistant to make sure the connections are working properly.<sup>8</sup> Once that's been accomplished, she sends the child's care plan to the staff as an e-mail attachment. Some clinical sites allow sharing of documents through their EHRs, which allows all professionals to access the same patient-related information without requiring additional steps.

### *Visit 3: Readjusting Jennifer's Care Plan*

Although a care plan has been put in place and all members of the care team have been doing their best to help Jennifer maintain control of her condition, she experiences several episodes of hypoglycemia that have her and her parents worried. These problems prompt another visit to her pediatrician to determine the cause and to take a second look at the care plan and make appropriate adjustments.

A candid conversation between the pediatrician and Jennifer reveals that she is embarrassed to let others at school know about her diabetes and has tried to hide it from her classmates. At times, that has resulted in her not taking her insulin on time and, at other times, not timing her meals and snacks to coordinate with her insulin shot. Further, she is self-conscious about her weight and sometimes skips meals to avoid gaining weight; this has also contributed to hypoglycemic episodes.

To address these issues, the pediatrician reviews the signs and symptoms of hypoglycemia with Jennifer to make sure she knows how to identify when hypoglycemia may be occurring, what to expect, and how to respond when the situation emerges. He confirms that she has glucose tablets on hand at all times, especially at school, to address the problem. Jennifer confirms that she can identify the signs and symptoms of hypoglycemia if or when they emerge and has foods available to increase her blood sugar levels. The next step is to address psychosocial issues related to her condition.

The pediatrician delves a little deeper into these issues. Upon questioning, Jennifer admits to being bullied by a few of her classmates. To avoid drawing attention to herself, she has been trying to hide her condition and has not followed all instructions spelled out in the care plan that was originally agreed upon. The pediatrician offers some tips on how to cope with the situation, and also discusses the situation with Jennifer's parents. Now that the parents are aware of the underlying problem, they make

arrangements to address it with the Jennifer's teacher.

The American Academy of Pediatrics offers professional resources to help pediatric medical home teams address bullying and cyberbullying,<sup>9</sup> as well as patient education tools to cope with the problem.<sup>10</sup> The pediatrician shares these materials with Jennifer and her parents and adds them to the care plan.

### Summary

For patients like Jennifer Marconi, a care plan is an essential part of treatment; it allows her pediatrician, her parents, her school, specialists, community partners, and Jennifer to manage her diabetes. Everyone is on board with the care plan, and Jennifer is gradually developing the skills needed to manage her condition and all clinical and psychosocial issues it entails. She has become more expert at calculating her insulin and carbohydrate needs, her blood glucose levels are now under better control, her hypoglycemic episodes are less frequent, and she and her classmates have developed better relationships.

### Posttest

1. All children in a pediatric practice should have a care plan created to guide their treatments. True or **false?**

Explanation:

A care plan is not necessarily required for all patients. A child who comes into the office with an acute ear infection, for instance, but who is otherwise healthy, might receive a visit summary with patient instructions and have no need for a care plan.

2. A care plan should not only outline a child's medical treatment but also include an assessment of which of the following issues?
  - a. The child's and family's strengths and needs.
  - b. Social and developmental issues.
  - c. The child's educational needs.
  - d. Financial concerns.
  - e. All of the above.**

Explanation:

The care planning process starts with an understanding of the patient's and family's needs, strengths, and goals. This can happen only when the medical home team develops a strong, trusting relationship with the family. Once that takes shape and is solidified, the team can perform a comprehensive assessment of strengths, needs, and gaps, as well as address interrelated medical, social, developmental, psychological, behavioral, educational, environmental, mental health, community partnership, and financial concerns or needs.

3. Research suggests that failure to plan and coordinate care may be common in many primary care practices and can disrupt continuity of care. **True** or false?

Explanation:

Research suggests that poor care coordination is common in primary care practices and can have serious consequences. Research shows, for instance, that communication between primary care physicians and specialists is often inadequate, with too little or poor quality information changing hands to ensure the

best continuity of care. Part of the solution to this problem is a care plan that is shared among all caregivers and anyone working with a family and child to optimize his potential and functioning. This includes those in and outside the medical arena.

4. The care planning process can include reaching out to specialists through the use of any available electronic health record system, e-mail system, or text-messaging application. True or false?

Explanation:

Developing a good relationship when you're the specialist that your patients see is an important part of the care planning process. Any electronic communication with other professionals, however, must adhere to federal regulations spelled out in the HIPAA (Health Insurance Portability and Accountability Act). All text messages and e-mails should be sent through a secure, encrypted system that is HIPAA compliant.<sup>8</sup>

### Reflections to Consider

The following questions are meant to prompt thought and discussion either individually or in a small group. There are no right or wrong answers.

- What are some critical components of a care plan you think should be included in caring for your patients?
- Think about a time you have developed a care plan for a child. What went well? What are some areas of opportunities for improvement? If you have never developed a care plan with a family before, think about how you would approach creating that care plan. What strategies would you employ to ensure the family/youth engage in the creation of the care plan?
- Which community partners have you partnered with that would be helpful to engage in care planning. Think about how you would approach partnering with them.

### References

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<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Medical-Home-for-Children-and-Adolescents-Exposed-to-Violence/Pages/Bullying-and-Cyberbullying.aspx>.  
Accessed July 16, 2015
10. American Academy of Pediatrics. Bullying: It's not OK. Connected Kids Web site.  
<http://www2.aap.org/connectedkids/samples/bullying.htm>. Accessed July 16, 2015

## Resources

Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs  
([http://www.lpfch.org/sites/default/files/field/publications/achieving\\_a\\_shared\\_plan\\_of\\_care\\_full.pdf](http://www.lpfch.org/sites/default/files/field/publications/achieving_a_shared_plan_of_care_full.pdf))

Building Your Medical Home: Sample Pediatric Care Plan  
(<https://medicalhomes.aap.org/Documents/PediatricCarePlan.pdf>)

American Academy of Pediatrics "Bullying: It's Not OK" Web page  
([www2.aap.org/connectedkids/samples/bullying.htm](http://www2.aap.org/connectedkids/samples/bullying.htm))

American Diabetes Association

- "Safe at School" Web page ([www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school-](http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school-))
- "Written Care Plans" Web page ([www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/written-care-plans](http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/written-care-plans))

National Center for Medical Home Implementation "Resources for Practices" Web page  
(<https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Practices.aspx>)

National Institute for Children's Health Quality Care Planning Resources  
(<http://medicalhome.nichq.org/resources/mh-care-planning-resources>)