

Patient Education Package: Hydroxyurea for Sickle Cell Disease

This patient education package was developed to support health care providers, who provide health education for children and families related to the use of Hydroxyurea, a medication used in the treatment of sickle cell disease (SCD). It is intended to: provide easy access to high quality, evidence based patient education resources (brochures, videos, testimonials etc.) that can be used according to the individual learning needs of children and families. Suggestions on how to develop additional materials and how to effectively use patient education resources with children and families can also be found.

Please note that this document utilizes the term ‘recipient’, which refers to patients and family members who are receiving health education regarding a health concern for which they are affected by and living with on a short-term or daily basis.

How to Effectively Use This Patient Education Package



1. Assess

- The recipient(s) of health education
- Circumstances around education



2. Customize Health Information

- Choose resources and strategies that will be most effective for the health education



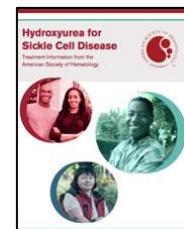
3. Evaluate Effectiveness

- Was the education effective?
- Did the recipient understand the key messages?
- Did the recipient retain what was taught?

Recommended Patient Education Resources for Families

a) Brochures

[Hydroxyurea for Sickle Cell Disease](#) by the American Society of Hematology



b) Videos

[Hydroxyurea Treatment for Children with Sickle Cell Disease](#) by Monroe Carell Jr. Children's Hospital at Vanderbilt

[Our Story: Living with and Managing Sickle Cell Disease](#) by the National Heart, Lung and Blood Institute

Recommended References for Healthcare Providers

National Institutes of Health Expert Panel. (2014). [Hydroxyurea Therapy in the Management of Sickle Cell Disease](#). In *Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014* (Chapter 5).

Additional Strategies for the Development and Dissemination of Patient Education Resources

a) Patient Testimonials

- A testimonial describes an individual or family's experience with Hydroxyurea and could be written, visual (video), audio (recorded) or in-person.
- Testimonial examples can be found on pages 6, 10, 11, 13 & 14 in the Hydroxyurea for sickle cell disease [brochure](#) above.
- Possible questions to help develop a testimonial:
 - What was life like before starting this medication?
 - Did you have any hesitation to using this medication? If yes, what was your concern?
 - What did you find as a result of this medication?
 - If you were to recommend this medication to your best friend, what would you say?
 - Is there anything you would like to add about this medication?

b) Regional Advocacy Groups

Provide information for patients and families regarding local advocacy groups.

c) Posters

Display posters in the clinic and inpatient unit promoting Hydroxyurea for the treatment of Sickle Cell Disease.

Best Practices for Effective Use of Patient Education Materials

Patient education materials should always be used as a tool to support a comprehensive patient education strategy, and not in isolation.



1. Assess using the PEEK Model: Physical, Emotional, Experiential, Knowledge Readiness¹

Physical:

- The best possible circumstances for doing teaching
- Timing – low stress, dedicated time when you will not be interrupted, avoid just before discharge
- Environment – quiet, private, familiar area

Emotional:

- Developmental level
- Frame of mind
- You could ask the recipient:
 - How do you feel about?
 - Are there any issues that might impact your learning right now?
 - What is on your mind right now regarding.....?

Knowledge:

- Present knowledge base/previous learning
- Cognitive ability and learning disabilities
- Literacy
- Health literacy
 - Ability to understand, process and use health information (verbal, written, visual etc.) in order to make informed decisions specific to one's health
 - Influenced by many factors, such as culture/language and knowledge of health topics & health care systems²



2. Customize Education

- Choose strategies & resources that will be most effective for the individual based on the PEEK Model.
- Personalize whatever patient education material/resource you are using by adding the patient's name, medicines, and/or specific care instructions.

Strategies

- Circle or highlight the most important points as you talk about them.
- Use materials that are colourful and interesting whenever possible.

- Review material with the recipient more than once as new learning requires repetition for comprehension. This can take place with different team members within clinic or inpatient visits.
- Use multiple strategies for teaching in order to meet the needs of different learning styles.
- When literacy level is low, consider strategies such as recording the discussion or reading the pamphlet.
- Use plain language. For example, saying “health problem” instead of “condition”. (*More examples at the end of the section*).
- Key elements of plain language include:
 - Order information from most important to least important
 - Break down information into simple, manageable sections
 - Use plain language as much as possible and explain any medical terminology
 - Clarify any misunderstandings before moving on. If there is a misunderstanding, try to explain it in a different way
- Document a brief summary of teaching provided, so you and other team members are aware of content that was previously reviewed, prior to the next hospital visit
- All patient education materials being used with patients and families should be reviewed on a regular basis to ensure they are up to date and reflect current practice



3. Evaluate Effectiveness

- Checking for comprehension can lead to better health outcomes.
- Use **teach-back method** to confirm understanding. Ask the recipient to explain back to you— in their own everyday words. You could ask the recipient:
 - “Just to be sure I’ve explained this well... can you describe what I’ve said, as you would to a friend?”
 - “Can you show me how you will do this yourself (i.e. administer medication) when you leave here, so I’ll know if I’ve explained it clearly?”
- Use open-ended questions to assess understanding. You could ask the recipient:
 - What things will you be looking out for?
 - When will you need to call us, or come in?
 - Is there anything I did not explain well? Anything I missed that you wanted or expected to hear and learn about?
 - Do you have any questions?
- Avoid questions like “Did you understand that?”

¹ White, K.M., & Dudley-Brown, S. (2012). *Translation of evidence into nursing and health care practice*. New York, NY: Springer Publishing Company.

² U.S. Department of Health & Human Services. (2008, July 24). Health literacy basics. In *Quick guide to health literacy*. Retrieved from <https://healthliteracycentre.eu/wp-content/uploads/2015/11/Quick-guide-to-health-literacy.pdf>

Plain Language Examples

	Problem Word:	Consider Using:
<p>Medical Words Frequently used by clinicians in healthcare</p>	<p>Condition</p> <p>Dysfunction</p> <p>Oral</p> <p>Procedure</p> <p>Symptom</p> <p>Benign Growth /Tumor</p>	<p>Health problem/concern, how you feel</p> <p>Problem</p> <p>By mouth</p> <p>Something done to treat/investigate your problem</p> <p>What is not feeling right</p> <p>Not cancer</p>
<p>Concept Words Words used to describe an idea, metaphor or notion.</p>	<p>Adverse</p> <p>Cognitive</p> <p>Hazardous</p> <p>Generic</p> <p>Support</p>	<p>Bad</p> <p>Learning, Thinking</p> <p>Not safe; dangerous</p> <p>Product without a brand name</p> <p>Help with your needs</p>
<p>Category Words Words that describe a group or sub-set</p>	<p>Avoid</p> <p>Intake</p> <p>Option</p> <p>Referral</p> <p>Wellness</p>	<p>Stay away from</p> <p>What goes into your body (eat or drink)</p> <p>Choice</p> <p>See another doctor, second opinion</p> <p>Good health</p>
<p>Value Judgement Words Words that may need an example or visual to convey their meaning.</p>	<p>Adequate</p> <p>Cautiously</p> <p>Moderately</p> <p>Routinely</p> <p>Temporary</p>	<p>Enough</p> <p>With care; slowly</p> <p>Not too much</p> <p>At the same time every day/week/month</p> <p>For a little while</p>

References

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White, K.M., & Dudley-Brown, S. (2012). *Translation of evidence into nursing and health care practice*. New York, NY: Springer Publishing Company.

This education package is intended for clinicians to consider using based on assessment of fit with your organization's policies, procedures and specific context. The education package is reflective of best practice at the time of sending and should be assessed at regular intervals to ensure it continues to reflect current best practice with regards to hydroxyurea for sickle cell disease.