



Grief and Alopecia Areata



An informative brochure on the grieving
process that can accompany hair loss

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Alopecia Areata:

Hair Loss and the Grieving Process

A diagnosis of Alopecia Areata, or similar disorders that result in hair loss can, of course, be devastating news for a person. Some people are fortunate enough to be able to quickly adapt to the unpredictable (and often extreme) changes to their appearance with little or no impact on their lives. However, for the majority of people a diagnosis of Alopecia Areata often results in a negative psychological impact. Men, women and children alike are at high risk of experiencing various emotional problems that can occur regardless of whether the hair loss can be easily masked, or whether the loss is a much larger patch that is impossible to hide.

In the initial stages of hair loss, it is common to experience an associated *grieving process* for the loss. This is considered a normal reaction that is a necessary part of learning to cope with the changes to appearance. After all, a person's hair is more than "just hair"; it also makes up a great portion of the identity of that person.

The following information seeks to help explain what can typically be expected during the grieving process associated with hair loss. It may assist people struggling with adjustment to manage the changes to their appearance.

Understanding Alopecia Areata and Grief



Before discussing the typical stages of the grief process for hair loss, some important things to note are:

The process of grieving is a healthy reaction. It is often a very difficult experience, but grieving following loss is a *normal* reaction. A person may experience a variety of emotions including sadness, depression, hopelessness, guilt, fear, isolation, loneliness, anger and frustration. It's okay to feel sad and to cry, and this can be a necessary step in the process for some people.

Grief is a process, not an event. This is true for people of all ages. Grief is not a mental state, nor a specific kind of feeling such as sadness. Indeed, it is possible to be happy or sad, or experience any type of emotion during the grieving process. It is important to remember that somebody who is grieving may not necessarily be sad all the time. There are typically different stages of grief, and it is possible to have ups and downs throughout the process.

Grieving for/about?? hair loss is a unique process. Although there may be some similarities, the grieving process of hair loss should *not* be compared with other types of grief, such as mourning the death of a loved one, or the grief experienced as a reaction to a terminal illness. All types of grief usually follow a characteristic pattern, but each type follows a distinct series of stages unique to the type of loss experienced.

Everyone experiences grief differently. Just as every person

is different, every person's reaction to hair loss is different too. Learning to come to grips with a diagnosis of Alopecia Areata can depend on characteristics such as age and gender, *or* it can be a very different experience for two similar people. Most people go through a grieving process that can range in time from a few weeks to a few months. Everyone is very different when it comes to the emotions they experience after losing their hair.

Do not expect each of the stages of grief to follow in a rigid order. The information provided in this brochure is simply an explanatory tool to assist understanding. It is possible for people to experience stages of grief at different times and in different orders. There is not *one* way to grieve. In fact, trying to determine if you or someone close to you may be on a certain stage of the process, can be unhelpful if you try to conform to every symptom typically experienced at that stage. These stages are better used as a reference guide to understanding that the grieving process following hair loss can be a very broad experience, and these stages may or may not make up some of this experience.

Additional Information for Parents and Caregivers

Be honest. Children and adolescents will often see through false information and wonder why you do not trust them with the truth. Lies do not help in developing effective coping strategies for the changes to

appearance. When discussing information concerning hair loss, it can be difficult to offer insight into a disorder like alopecia that is both unpredictable and unexplainable. However, helping a child or adolescent to understand that this is the true nature of Alopecia Areata might make the grieving process a little less daunting.

Allow children the opportunity to explain their own grief process. Provide enough information at the level that your child or adolescent can understand, and then let them have the opportunity to tell their own story. This can promote helpful coping.

Be a good listener, and encourage questions. Let children know that you really want to understand what they are feeling or what they need. Sometimes children are upset but they cannot tell you what will be helpful. Being patient and encouraging the sharing of feelings with you may help. Don't worry about not knowing all the answers. If you don't know something, say so, and explain that you will try to find the answer together.

Children may need additional support networks. Try to develop alternative supports for children and adolescents outside of the family unit, such as peer group friendships.

Grief is hard work for children and hard work for adults as well. Be aware of your own needs. It is important to remember that you and others may need support too.

The Grieving Process and Alopecia Areata

1. SHOCK AND DENIAL

- The immediate reaction is usually numbed disbelief. This is shock, and it may provide you with emotional protection from being overwhelmed all at once.
- The unpredictable nature (relapse) of Alopecia Areata can make acceptance difficult and denial may come about at some level as a way to avoid the pain.

2. PAIN AND GUILT

- As the shock wears off, it may be replaced with emotional pain. Although this may be almost unbearable, it is important the pain is experienced at some level, and that it is not hidden, avoided, or escaped from with alcohol or drugs.
- Some people may have guilty feelings or remorse over things they did or didn't do. Indeed, you might find yourself thinking that you may have caused your hair loss somehow. Life may be frightening or chaotic during this phase and although the condition can be irrational in cause and relapse, it is important that *you* try to remain rational and seek advice from professionals.

3. ANGER AND BARGAINING

- Frustration may give way to anger, and some people may lash out and lay unwarranted blame for loss on others. Behaving in this way may damage relations with others. There is also the possibility of anger being turned in on oneself in the grieving process.
- This is a time for the release of bottled up emotion. Trying to aim the anger in a productive manner, such as with exercise can be helpful.
- You may rail against fate, questioning 'Why me?' You may also try to bargain in vain with the powers that be for a way out of your despair (i.e.: 'I will do anything, just fix my problems'). It is important to try to be rational during this period.

4. DEPRESSION, REFLECTION AND LONELINESS

- Just when others may think you should be getting on with your life, a long period of sad reflection may overtake you. This is a normal stage of grief, so do not be 'talked out of it' by well meaning outsiders. Encouragement from others may not be helpful to you during this stage of grieving.
- During this time, you may finally realize the true magnitude of your loss, and it can depress you. You may isolate yourself on purpose,

DEPRESSION, REFLECTION AND LONELINESS (cont.)

reflect on things you did in the past, and focus on memories of the past. You may sense feelings of emptiness and despair. This stage will not always pass after a short period of time, but it is passable.

- Psychological studies have found that anxiety and depressive disorders occur in higher rates in people with Alopecia Areata when compared to people without the disorder. Nevertheless, grief and major depressive disorder are *not* the same. The symptoms are similar, but major depressive disorder is a clinical disorder that is usually much more intense. Therefore, grief can progress to depression. If you feel extremely depressed all day *and* everyday for a fortnight or more and you cannot function, then it is strongly advised that you speak to your doctor about seeking assistance.

7. THE UPWARD TURN

- This stage can be difficult to get to, and may be easier to reach with outside help.
- As you start to adjust to life with Alopecia Areata, day-to-day activities become a little calmer and more organized.
- Your physical and psychological symptoms of grief lessen, and your 'depression' begins to lift slightly.

6. RECONSTRUCTION AND WORKING THROUGH

- As you become more functional, your mind starts working again, and you will find yourself seeking realistic solutions to problems posed by Alopecia Areata.
- You will start to work on practical and financial problems and rebuild your identity and life with Alopecia Areata.

5. ACCEPTANCE AND HOPE

- During this, the last of the seven stages in this grief model, you learn to accept and deal with the reality of your situation.
- Acceptance does not necessarily mean instant happiness. Given the psychological pain and turmoil you have experienced, it takes time to find a way forward.
- You will start to look forward to and actually plan things for the future. Eventually, you will be able to think about your loss without pain or sadness, but for now, the wrenching initial pain will be gone.
- You will once again anticipate some good times to come, and yes, even find joy again in the experience of living.



Coping:

Additional Information



Are you not coping?

If you don't think that you are adjusting to changes in a positive way after several months, and find that your feelings of sadness are affecting how you function at work, at school, or at home, then it is strongly encouraged that you speak to your doctor.

- Don't be afraid to ask for help.
- Talk to other people with Alopecia Areata, or join a support group through the AAAPF.
- Talking to your doctor to get accurate information about your hair loss can help with coping *and* with the grieving process.
- Some doctors may be unaware of the psychological impact associated with Alopecia Areata, or may seem to lack empathy. If you are dissatisfied, then seek another opinion.



Helping others cope

If you know somebody close to you with Alopecia Areata, you may feel helpless at times. Although you cannot "cure" the disorder, you can:

- Let the person know that you are there for them, and *show* you care.
- Offer practical support. Don't presume you know the cause, or the solution.
- Let the person make their own decisions on their healthcare. If they are young, then let them be involved in the decision-making process. .
- Don't take anger personally and accept strong emotions.
- Be patient and listen. Don't say you "know" or "understand", unless you really do.
- Take care of *yourself* too. Be mindful of what you can, and can't do.



The Grief Process for Children and Adolescents

It is common that children and adolescents also experience a grieving process in response to hair loss. This process can be very different to that commonly experienced by adults.

There is no right or wrong way to help children and adolescents cope with Alopecia Areata. However, by appreciating how children of different ages understand what is happening and the behaviours that might result, it will be easier to talk and play with your child in ways that promote understanding and helpful coping.

There are typical behaviours for children and adolescents of different ages when it comes to grieving for their hair loss, but just as with adults, the grieving process for children and adolescents does not necessarily follow a specific pattern. The process is likely to depend on individual temperament and age. Nevertheless, each person is unique regardless of his or her age, and the grieving process is therefore also unique.



Pre-school Age Children

The grieving process for a pre-school child is obviously very different when compared to the process that older children and adults typically may experience. Pre-school children may not be aware that hair loss is taking place, or if aware, the child may not fully understand or appreciate the fact. It is typical behaviour of a pre-school aged child to carry on as if the hair loss is unimportant.



The grieving process may only become apparent when the child notices that the family behaviour has changed toward them. Grief at this age may then be expressed primarily through behaviours such as crying, clinging and withdrawal. Emotional reactions such as anger and sadness are also typically displayed.

It can be helpful for parents and carers to provide children with reassurance in the form of love and attention, but it is more important to try to maintain “normal” interactions. That is, try not to make a “big deal” out of the hair loss, while ensuring your child feels accepted and loved. Children always benefit from consistency, and reassurances that everything is going to be okay may help.





Pre-adolescence (typically children under the age of 10 years):

Pre-adolescent children may also not react to their hair loss. However, reactions to hair loss at this age can also be misinterpreted, because some children may not seem to be affected on the surface. Children may grieve through their play and imaginative expression, and it is therefore important to be mindful of *any* changes in their daily functioning.

Children will be aware of the reactions of significant adults as they interpret and react to the situation. Similar to pre-school children, adult reactions will play an especially important role in shaping a primary grade child's perception of the hair loss. Additionally, peers at school and elsewhere may tease or bully, and bring the hair loss into a more acute focus. The grief process may be displayed through:

- **Emotions** including anger, panic, confusion, fear of being alone, withdrawal and sadness. An initial period of **shock** and at times an apparent lack of emotions may help the child detach from the pain of the moment.
- **Behaviours** can include crying, changes in eating and sleeping patterns and problems at school in regard to performance. Regressive (immature) behaviours, such as needing to be rocked or held, or difficulty separating from parents or significant others can also be a reaction to the hair loss. If children feel insecure, they may misbehave as a way to seek control over a situation for which they have little or no control.

These reactions are typical and should not be a cause for alarm, unless they persist for an extended period of time. Parents and carers play a major role in helping a child deal with the grieving process. It can be helpful to:

- Reassure children they will be taken care of and that they are not to blame. Provide comfort and physical support, such as cuddling.
- Provide simple answers to their questions—try not to offer more information than asked for if the child is very young. Be clear and honest, and sensitive to the language used. Be prepared for unusual questions. Children may ask the same questions over and over, not because they do not understand the answers, but usually because the hair loss can be hard to believe or accept. Some children may be very mature when it comes to understanding the implications of their hair loss, and they may ask about what is happening and why. **Alopecia Areata** is very unpredictable, so it is important to avoid providing unrealistic reassurances about the future.
- Help children find words to express their feelings. Promote conversations about how they feel and be a good listener. Explain that they will always have feelings about their hairloss, but they will not always be so powerful all of the time. Trying not to “make a big deal” out of the hair loss can help a child adapt to the changes.
- Tears can help wash away grief. Crying is okay, as long as it isn't *all* the time.



Adolescents (typically +10) and young teenagers:

Most adolescents are able to understand the details of their hair loss. Teenage years are difficult enough with hormonal changes, interactions with the opposite sex and other big life changes. Therefore, the grieving process associated with hair loss can be extremely hard at this age. The grieving process may follow a pattern similar to that typically experienced by an adult, and/or may be expressed through:

- **Volatile emotions.** These are typical of all adolescents; however, experiencing alopecia at this age can make a person's emotions much more intense. The initial shock can lead to denial. This may then be quickly followed by frequent and powerful feelings, such as anger, terror, frustration, helplessness, anxiety, sadness, depression and fear.
- **Behavioural reactions.** These may include risk-taking activities, self-destructive behaviours, drug/alcohol use, isolation, changes in eating and sleeping patterns, suicidal thoughts, and withdrawal from peers and school. Misbehaviour may reflect insecurity and a way to seek control over a situation for which they have little or no control. A sharp drop in school performance and attendance may also occur.

Hair loss can be especially devastating for adolescents and teenagers due to the impact on the person's identity and the loss of desire to want to interact with friends, peers, or possibly everyone they know. Therefore, Alopecia Areata can put a teenager at a high risk of developing psychological issues, such as depressive or anxiety disorders. It may be helpful for parents or carers to:

- Listen to your child's fears, thoughts and concerns. Honest and open discussions that include your child in decisions can promote at least some control for them in the situation. Some parents or carers may need support in understanding their own emotions and how to verbalize their feelings. Be patient.
- Provide comfort, support and realistic reassurances. Peer support and other supportive adults can be very important; parents and careers need to encourage these interactions.
- Grieving can be a slow process. However, if you are worried that your child is not learning to cope in a positive way with their hair loss, be prepared to seek some outside help. For example, if your adolescent is experiencing an extended period of depression where they never want to leave the house, then carefully broach this topic of outside help with them, and speak to their doctor about options. Many mental health professionals specialize in positive coping strategies.



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