

# Stepping Back



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## Introduction

by Amanda Gray – HemiHelp Home and School Visitor

This booklet aims to give guidance and support to parents of teenagers coming up to and going through the transition stage of life in the 16 plus age range. This resource will recognise and address some of the issues young people with hemiplegia might face as they move on to becoming an independent adult. This can be a difficult time for all young people, but it can be especially challenging for a young person with hemiplegia, who probably has a few more obstacles to overcome beyond those of the average teenager going through this same stage. In the same way, by default, it can also be one of the hardest stages to navigate for their parents.

In my job as HemiHelp Home and School Visitor, I have gained a lot of experience and knowledge regarding the issues of transition. However, my most crucial experience comes from being a parent of a teenager currently going through this phase.

Up until the transition stage, we (parents) are hugely important in the child's life. To some degree we have all had to be involved more than we ever planned or expected to, especially when one considers how many medical, educational and social milestones the child has probably already gone through. As these teenagers rapidly head towards young adulthood, the most pressing change for them is the ability to become more independent from the parents who have been the central support up until now. This does *not* mean that there will be an exact date and time where you will

be expected to step back and leave your son or daughter alone to make all decisions and choices. But it does mean that we, as parents, can be just as supportive and helpful to our sons or daughters by stepping back a little at a time.

Many parents I have met over the years have had appropriate and understandable anxieties and fears about this stage of their son/daughter's life. After all the years protecting our children and adapting life to make it as easy as possible for them; and after all of the input we have provided for their wellbeing and development, it can be quite overwhelming to think that it can ever be any different.

As we try to come to terms with our fears, the first time our son/daughter stumbles at some level, we are understandably anxious to step in and take back the reins. That is not necessarily the best action to take, just the most natural reaction for a parent. Maybe what we could do is take a step back towards the situation and give temporary support till the bump is ironed out, but then feel able to



*“Quite often your son/daughter is not only ready for the next step of independence, but they also want that independence.”*

take that same step back to keep the process of independence and transition moving forward for that young person.

Quite often your son/daughter is not only ready for the next step of independence, but they also *want* that independence. They don't expect it to be sudden, but a little at a time, with the sense that the stabilisers (parents) are still there to keep them safe if they start to get a wobbly wheel!

As school life is a hugely important aspect to a young person's life experience and sense of self, it is probably the main influence on when a young person feels ready to move on and take more responsibility for his/her self in all areas of their life. So I believe that from the early teen years, the best way to support our sons and daughters is by encouraging them to make their own choices/decisions on most of the issues in their lives. This puts the young person in the



*lead position* before the more difficult and stressful transition stage between leaving school and moving on to further education/work choices.

It is also worth bearing in mind that nobody expects that the young person will wake up one day suddenly fully independent and ready to make all those adult decisions and choices we make on a day to day basis. That would be unrealistic for anybody and it will be a gradual process. Therefore the caveat is always that a parent is sensible to help the process move along gently, but positively and progressively over a long period of time.

I believe that all of our sons/daughters will navigate the transition stages admirably and successfully, although to varying degrees, and at their own pace. I also believe that the time of transition for us as parents is one where we can become confident and positive that anything and all things are achievable for our sons/daughters. And for that to happen we need to accept and feel positive about stepping back a little at a time!

**Note:** references in this booklet to parents also apply to carers.



## Practical hints and tips

When we consider how children move through life stages we know that it is the natural order of life that children want to, and do successfully make their way through transition from childhood to young adulthood. Young people usually make it quite clear that they no longer want, nor need the constant parental input.

The more we step back as our child's support, the more they have the freedom to make their own choices and decisions. This can be done slowly over a long period of time. It is useful for us parents to gradually lessen our input from as early on as possible (probably the early teenage years) as the young person successfully manages each independent aspect of his/ her life.

There are some very practical issues to consider when we are encouraging our son/daughter to take the mantle of independence. This section outlines some of these areas and offers hints and tips for you as the parent to encourage independence and 'step back' where appropriate:

### School and work

- Ensure your son/daughter attends all of their IEP (Individual Education Plan) meetings whilst at school/6<sup>th</sup> form. This will enable them to be responsible for their school choices and future work opportunities.



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- Encourage your son/daughter to take care of their health care issues at school. This will be a good preparation for managing healthcare issues in the workplace. You could develop a personal passport (template available from HemiHelp) together and have a clear plan of what to do in a medical emergency.
  - Talk to your son/daughter about what types of jobs and careers interest him/her. Discuss which subjects would be relevant to these jobs.
  - Your son/daughter can contact HemiHelp's Transitions Adviser for 1-to-1 support, for everything including: how to search for jobs, applying for jobs, higher education, interview preparation and interview techniques.
  - Your son/daughter can look into the Access to Work Scheme. They may be eligible for a grant to cover extra employment costs which arise because of their condition (support workers, specialist equipment, adaptations to premises, travel, awareness training for fellow employees).

### Friendships and relationships

- Encourage your son/daughter to join clubs to meet people with shared interests.
- Encourage your son/daughter to chat to other young people with hemiplegia (and without). It can be reassuring to know other people with shared experiences (as well as those with other perspectives). HemiHelp has a Facebook group, Pen Pal scheme, events for young people and a mentor scheme.

- Relationships are an important part of life. It is crucial for parents to feel confident to talk to their son/daughter about sex and relationships and to have the right information to help them make responsible, safe decisions about their health, body, emotions and relationships. HemiHelp has an information sheet about friendships and relationships, this can be accessed here: [www.hemihelp.org.uk/about\\_us/what\\_we\\_do/young\\_adults/friendships\\_and\\_relationships](http://www.hemihelp.org.uk/about_us/what_we_do/young_adults/friendships_and_relationships)

### Independent living

- Give your son/daughter chores and responsibilities at home and in the family from an early age. This sends the message that you feel they are capable and you can introduce different tasks step by step.
- Introduce opportunities for your son/daughter to prepare their own meals. This becomes increasingly important if they are going to be living independently, at university or elsewhere.
- Online shopping can be a good way to accomplish the weekly shop.
- If your son/daughter finds chores or cooking difficult and frustrating, help them look for solutions, the HemiHelp Facebook group can be useful for learning from others' experiences.
- Consider how your son/daughter travels to school and to social events. If you have always driven them to school, there may be other ways for them to get to school under their own steam instead. For example, using public transport part of the way to and from school if feasible, or you could drive them part way to school and



they could walk the rest of the way with friends. For some young people with hemiplegia, it is not appropriate or possible to travel under their own steam. But when it is possible, it is a good and useful example of how independence can be introduced into their life.

- Many people with hemiplegia can and want to learn to drive. HemiHelp has a specific information resource on driving, you can access this here: [www.hemihelp.org.uk/families/activities/driving](http://www.hemihelp.org.uk/families/activities/driving)
- Some young people with hemiplegia find handling money difficult. Nowadays most shops/restaurants accept debit cards and this can be easier to handle. You could support your son/daughter in setting up their own bank account, the Money Advice Service offers impartial advice on managing money - [www.moneyadviceservice.org.uk](http://www.moneyadviceservice.org.uk)
- Entitlement to benefits for disabled people is particularly complex and can't be covered in detail here, but here are a few points to consider:

*If you currently receive DLA (Disabled Living Allowance) for your son/daughters' care needs, this will change to PIP (Personal Independence Payment) for all young people from age 16.*

*It is a good idea to complete the PIP application form together, adding as much detail as you can.*

*You can support your son/daughter by being organised and understanding what they are entitled to.*

**If you would like further support with this, please contact the HemiHelp office and speak to our Transitions Adviser.**

## Managing their own healthcare

You may know already that the older your son/daughter gets, the more the professionals will deal directly with them in appointments. This is to encourage them to take responsibility and choices for their own health and wellbeing.

- Help your son/daughter to make a list of questions to ask their doctor/physio/OT at each appointment, and remind them to bring the list and ask the questions.
- Encourage your son/daughter to talk to the medical professional and to answer questions directly, rather than you talking on their behalf.
- Allow your son/daughter to spend time alone with the doctor during appointments so they can ask any questions that may be uncomfortable in front of parents.
- Help your son/daughter to create a "portable medical summary" that includes a list of diagnoses, medications, allergies, prior surgeries and contact information for healthcare providers.
- Encourage your son/daughter to make their own appointments.

The above are just brief examples of transition stages for your son/daughter heading towards ultimately being happy, confident and independent to the degree he/she wants to be or can be. If you would like to discuss any of these topics in more detail, please contact the HemiHelp office.



## A parent's perspective

by Barbara Humphries

I have always tried to make Amie as independent as possible, but it has not been easy. Even now when she is at university I still have trouble letting go and I *never* stop worrying. In this section I share a few of my insights as Amie's mum and some of the experiences we (my husband and I) encountered as we supported Amie in becoming an independent adult. It has been quite a journey with challenges, upsets, achievements and lots of fun along the way.

When Amie was younger she had very little trust in other adults. The only people she wanted to be with were me, her dad or my mum. Sleepovers at about eight or nine years of age usually ended up with us picking her up about midnight, absolutely distraught. So instead, we used to have Amie's friends to stay at our house. Then, when her confidence grew and she wanted to go to a sleepover again, we explained to the parent she may not stay - this took the pressure off. We found if we gave Amie a 'get out clause' she never took it, but she needed to know it was there.

School residential trips were also a challenge. Our approach to this was to stay about 30 minutes away from the place she was staying. We had some lovely holidays in interesting places and Amie knew



if she needed us we could get to her quickly and she wouldn't have to be sent home.

When it came to new activities that Amie wanted to try, we would talk about it first and search for clubs or groups locally. One activity was horse riding. This was when Amie was about 14. Amie had always done RDA (Riding for the Disabled), but wanted to ride 'normally'. She was very worried that they would expect her to use both hands, etc. I spoke to the school and explained her difficulties.

I went with her the first time and stood by the fence so that I could support her if they asked or demanded her to do something she physically couldn't do. I found it really hard at first not to jump in and speak for her, so we arranged a signal that she could give me if she wanted me to help explain something to the instructor.

Over the next few weeks I moved away from the fence but still within 'shouting' distance. Then I used to sit in the car but still watching so I could see the signal. As her confidence in her instructor grew and she felt comfortable saying 'I can't do that, can we try it another way?' I was able to drop her off and pick up an hour later.

***"This I suppose was always our Plan A – letting Amie do what she wanted to do on her own. But always having a Plan B – Mum or Dad to help explain or give extra support."***

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*“Amie passed her test first time and I still remember how worried I was the first time she went out on her own. But I think that is what all parents feel.”*

This I suppose was always our Plan A – letting Amie do what she wanted to do on her own. But always having a Plan B – Mum or Dad to help explain or give extra support.

Another example where Amie wanted more independence was shopping with friends. Our Plan B for this was that I would stay in the town and do my own thing. If Amie wanted to try on some clothes, she would phone me and I would help her in the changing room. I would then leave her to buy the clothes and carry on with her friends. Amie finds handling money very hard, so a debit card makes this much easier.

When Amie reached 17 she wanted to learn to drive. We got her an adapted Motability car and found a recommended instructor. It was great to see Amie’s confidence increase as her driving improved. Amie passed her test first time and I still remember how worried I was the first time she went out on her own. But I think that is what all parents feel.

Amie went to a special school from Year 7 to Year 11. She then went to mainstream college and studied Animal Management. Part of the course required Amie to complete five weeks of work experience each year. I was worried how she would cope in a working

environment, but all of the placements were very supportive. By this stage Amie felt confident enough to ask for support if she needed to find a different way of doing things. One placement was a bird of prey centre an hour away from home. Amie decided she would stay in a hotel for the week as to add two hours of travel every day would be too tiring. As it happened living away from home for that week was more stressful than the two hours travel a day would have been. We had agreed to meet her for dinner one night. Then I decided to stay for a couple of nights so she could complete the work placement and have a positive experience.

Amie decided she wanted to go to university in Bangor in North Wales (five hours away from home). We did lots of research and thought we had all the support in place to make it work. But it didn’t pan out as we had expected. The university didn’t inform the staff about her anxieties or her level of fatigue and so the whole thing came tumbling down. Anxiety and fatigue levels went sky high and she had to come home. We reflected on what went wrong, talked about whether university was right for her and took time to rebuild her confidence. A year later she went to the University of Kent (one and a half hours from home). We have found this to be a much more supportive university. Amie knows if she needs to come home for a good night’s sleep, or simply a bit of TLC, she can do.

Now that Amie is at university I am finding it quite hard. I have lost the role I have had for the last 20 years – that of being her carer. But I know it is what happens, and I have given her the independence that she needs. I just have to find another role now. I think this is something that all parents go through when their chicks fly the nest!





## Changing relationships

by Gillian Leno

The transition from childhood to being a young adult is one which brings a very special set of challenges for parents and young people alike. As a PSHE (Personal, Social & Health Education) specialist based in a residential college for young people with additional needs, I have the privilege of being able to share some of my experiences of how young people deal with transition from the 'other side'. This helps me in my work with parents of my students and also in my work externally with organisations like HemiHelp.

Whilst we all prepare for the more practical changes that take place during the transition period, it is often the case – as in so many things – that the emotional changes and their subsequent effects on relationships get missed. This is something I hear about very frequently, not only from parents, but also from young people. Whilst change is natural and can bring with it many positives, it can also be exhausting and tricky to navigate. In this section we look at a couple of key points.

### Risky business

One of the big issues that is often raised as a concern by parents is the exposure to new risks that their son/daughter is going to face, as well as the matter of normal risk taking behaviour that young people naturally get involved with. It is a tricky subject, because we all gauge risk by our experiences: as adults who have had more experience, we are naturally more able to spot the risks! It is then instinctive to try and protect young people from them, because we really do know what the consequences of 'risk taking' behaviour could be.

However, if there is one thing that I can confidently share, it is that the experiences that teach us about risk have to be lived - it is this engrained instinct that young people are responding to. As adults it is useful to model our experiences positively and be upfront and balanced about what the outcomes could be. Don't forget that the reason that young people want to have experiences is to figure out *for themselves* what it feels like. Denying or invalidating that opportunity is likely to make them feel misunderstood or ignored.

### I'm not a child!

One of the main issues that this can lead to is conflict: parents try to be protective and young people interpret this as being controlling or trying to spoil their fun! Whilst this is almost inevitable at some point, it can be useful to try and limit the damage that this can cause.



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*“But it is more constructive to think of it as handing control over and stepping back, rather than letting go completely.”*

Constant conflict around the ‘letting go’ process can end up with everyone feeling hurt, isolated and ignored. These can be very hard to come back from.

Parents are often far more fearful than their son or daughter about the changes in the relationship and the issues that they raise as points of concern. This is natural because as adults we have more experience and we know the outcomes. However, young people will not be able to relate to this until they have shared the learning for themselves.

It is important not to project our own fears and frustrations onto either the relationship itself or any arguments or conflict that can arise. Fear can be picked up on in many different ways of course – but it is rarely helpful. Young people may either internalise them and ‘learn’ the fears (which can curtail their natural instincts to have developmental experiences from which to learn); or they may feel more determined to try things and take risks just to prove their parent wrong. In either case, what is certain is that decisions formed through fear will be more harmful than those made with a balanced approach, and are more likely to have a negative outcome.

Confident, calm conversations which acknowledge the young person’s feelings and curiosity (and need to have experiences) will usually be more supportive than overt attempts to protect.

It is important that parents’ fear of letting go is not projected onto the young person. Relinquishing control can be a frightening prospect and in many ways, this is exactly what transition represents. But it is more constructive to think of it as handing control over and stepping back, rather than letting go completely.

Ideas and strategies which have been helpful for the parents that I work with have included doing some research on areas which cause particular concern – for example, social media, contraception/sexual health and drug/alcohol use. Particularly useful websites are [www.thinkuknow.co.uk](http://www.thinkuknow.co.uk), [www.brook.org.uk](http://www.brook.org.uk), and [www.talktofrank.com](http://www.talktofrank.com). A little extra knowledge can go a long way towards putting parents’ minds at rest and increasing confidence when talking about risk.



Having any teenager going through transition is not the easiest time in life for parents and family members, but it is important to recognise that for a young person with hemiplegia, the level of anxiety may be higher and hard for them to voice. These feelings of anxiety and fear can manifest as resentment and anger towards the people closest to them, this can be very tough to cope with as you try to support your son/daughter through new challenges. There are a number of places you can get support from:

- The HemiHelp Helpline is available 10am – 1pm Monday to Friday during school term time, speak to a trained volunteer who has direct experience of hemiplegia - **0845 123 2372**
- HemiHelp has a Facebook group where lots of parents and adults with hemiplegia offer mutual support and share experiences - join here [www.facebook.com/groups/5512952137](http://www.facebook.com/groups/5512952137) or call the HemiHelp office (**0845 120 3713**) for more information.



## Action planning for independence

Stephen Gardner -  
HemiHelp Transitions Adviser

***"Independent Living enables us as disabled people to achieve our own goals and live our own lives in the way that we choose for ourselves."***

There are many challenges to living independently, some of which have been mentioned in this booklet. It might seem overwhelming at first but with the help of tools such as action plans, the process can be broken down in small, manageable steps which can be achieved more easily.

We use action planning at HemiHelp to support our members with virtually all aspects of independent living, from money management, to looking for work and shopping. It is a great framework for us to keep up with all aspects of the transition process, and keeps us on the right path when supporting others.

This section will outline what action planning is and how to draw up an action plan, so you can work through this process with your son/daughter.

***"We use action planning at HemiHelp to support our members with virtually all aspects of independent living, from money management, to looking for work and shopping."***





## What is Action Planning?

Action planning is a process which will help your son/daughter to focus their ideas and to decide what steps they need to take to achieve particular goals that they may have. An action plan is a statement of what you want to achieve over a given period of time. It is extremely flexible and can be applied to virtually any situation or scenario, from finding a job to losing weight!

It involves:

- Identifying a goal
- Setting objectives which are SMART

**Specific** – What exactly are you going to do?

**Measurable** – You need to be able to track progress; this can be framed by ‘how much or how many’.

**Achievable** – Be realistic; losing 10 lbs. in 3 months is achievable, where losing 10 lbs. in 3 days is not achievable.

**Relevant** – Your goal should be important to you.

**Time Frame** – When do you want to accomplish your goal? Select a date in the future.

- Prioritising tasks effectively



- Identifying the steps needed to achieve the goals that have been set
- Completing tasks to a deadline
- Reviewing the plan and altering if necessary

Writing down your goals turns them into a plan, not a dream. An effective action plan should give you a concrete timetable and set of clearly defined steps to help you to reach your objective. It helps you to focus your ideas and provides you with an answer to the question, ‘What do I need to obtain my objective?’

It’s fine to have several objectives, but you need to make a separate plan for each, otherwise things get confused.

If you write your commitments down on paper you tend to live up to what you have written down, as written commitments require more effort to make than verbal ones and there is also a physical reminder for you. The process of writing also seems to embed the commitment in your brain.

The action plan can be as simple, or as detailed as you want – just remember to use SMART targets to stay on the right path and remember to regularly REVIEW to check your progress and adjust the plan as necessary.

If you or your son/daughter would like support with action planning, please contact the HemiHelp office and speak to our Transitions Adviser.



# Action plan example

**My SMART goal is:** To attain full time employment in an office by the end of April 2015.

| STEPS  | ACTIONS  | RESOURCES  | ACTION DATE   |
|--|--|--|---|
| <b>STEP 1</b> Prepare CV   | <ul style="list-style-type: none"> <li>Find template</li> <li>Update template with my details</li> <li>Get this checked by two people</li> </ul>   | Contact HemiHelp's Transitions Adviser for professional input  | End of January 2015   |
| <b>STEP 2</b> Find relevant websites to search for jobs                            | Use most common websites: Jobs24, Charityjobs, Guardian website and speak to friends and family about finding others.  | Employment websites<br>Friends and family  | Immediately   |
| <b>STEP 3</b> Select relevant jobs that I want and have the relevant criteria      | Look for jobs that are suitable in terms of: <ul style="list-style-type: none"> <li>Salary</li> <li>Location and travel distance</li> <li>Duties required and experience wanted</li> </ul> | N/A  | Ongoing   |
| <b>STEP 4</b> Prepare cover letter   | Use internet and NCS (National Careers Service) to prepare suitable letter   | NCS  | Aim to have letter when CV has been reviewed.<br>End of Jan 2015. |
| <b>STEP 5</b> Apply for jobs   | Apply for jobs using revised CV and cover letter specific to each job advert. Contact HemiHelp's Transitions Adviser for advice on this.   | HemiHelp   | End of Jan.<br>Review progress and aim to increase number.        |
| <b>STEP 6</b> Follow up applications   | Ask for feedback from unsuccessful applications and ask for name to be put on file for any future vacancies  | Telephone/Internet   | As and when you have them.  |
| <b>STEP 7</b> Prepare for interviews/contact employer for feedback if unsuccessful | <ul style="list-style-type: none"> <li>Plan your travel to the interview</li> <li>Prepare interview answers</li> <li>Practice interview technique</li> </ul>                               | Look on Youtube for interview practice videos and tutorials. Ask someone to do a practice interview. | As and when you have unsuccessful applications to follow up on.   |

**I will monitor my progress by:**

Regularly reviewing my applications and seeing if I can improve my applications. Contact companies for feedback.

**My support team is:**

My mum, my dad, my best friend and Stephen, the HemiHelp Transition Adviser.

**I will discuss my goal progress with my support team on**

(select a date in the near future):

April 2015

**Celebrate your success!**

**Write down how you will celebrate your goal achievement:**

Taking Mum and Dad out for a meal and taking my best friend to the cinema!

# Action plan template

## My SMART goal is:

(To be motivating a goal needs to be challenging enough to stimulate us, but not so difficult that it is stretching but not highly stressful. Be precise about what you want to achieve and list the benefits

demoralising. It should be just outside your comfort zone, you would gain by achieving your goal)

|        | STEPS | ACTIONS | RESOURCES | ACTION DATE |
|--------|-------|---------|-----------|-------------|
| STEP 1 |       |         |           |             |
| STEP 2 |       |         |           |             |
| STEP 3 |       |         |           |             |
| STEP 4 |       |         |           |             |
| STEP 5 |       |         |           |             |
| STEP 6 |       |         |           |             |
| STEP 7 |       |         |           |             |

I will monitor my progress by:

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.....

.....

My support team is:

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.....

.....

I will discuss my goal progress with my support team on

(select a date in the near future):

.....

*Celebrate your success!*

Write down how you will celebrate your goal achievement:

.....

.....

.....



Supported by



HemiHelp's Transition Support Service provides 1:1 support on a range of issues including employment and benefits, independent living workshops and a mentoring scheme.

For more information contact the office and speak with our Transitions Adviser.

Helpline: **0845 123 2372** (Mon-Fri 10am-1pm)

Office: **0845 120 3713**

Email: **[support@hemihelp.org.uk](mailto:support@hemihelp.org.uk)**

Website: **[www.hemihelp.org.uk](http://www.hemihelp.org.uk)**

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