

MY SUPPORT PLAN

25th January 04

JOSEPH

This plan was drawn up by Caroline, Joseph's Mum with Joseph contributing in many different ways supported by his circle of friends and his family which comprises of:-

His Dad Robert, sister Rosie and brother Jacob

Deborah and Lee

Mandy and family

Clare and Jonny

Suzanne and family

June

Renee and Jack

Grandma and Grandad

Andrew and Roiseen

Catherine and family

Diane

Plus many other individuals who have helped Joseph along the way in his circle including Paul and Lynne in the early days when the planning first started.

Joseph has been privileged to have an ongoing person centred plan for the past 8 years. His plan's have used a variety of tools including Map, Path and Essential Lifestyle Planning. In the early days we used to plan in secret with friends, family and other potential allies, but now we feel confident and able to share Joseph's plans to the wider world. Joseph is now confident people are in a better position to listen to him and help him to action his plan.

Eight years ago part of Joseph's dream was to have a support plan which meant he could have the support to make real choices, develop real friendships and for him to live a life not dissimilar to his peers. The dream was never fulfilled until now as there was never a mechanism for doing this, we are now all excited about the future.

We are also now confident that we can open up the planning in the future to include a wider range of people to work in partnership with Joseph. This group of people will include people paid to be in Joseph's life, as we are now confident people do want to work with us and not against us. However, we must never forget this is a planning process with Joseph and no matter how long this process takes we must include him every step of the way.

This support plan has many appendices to back up the plan and has action's which will need to be addressed for the long term sustainability of the plan. We need to understand that Joseph is in a crucial stage in his life which is known as the 'Transition' to many people working within the services. For Joseph it is about planning his future, and at this stage the support plan will remain fluid and therefore will not be fixed in stone. To address the process we have developed the support plan in three phases which are based not years but are specific milestones in his life.

Caroline
Joseph's Mum

WHO AM I

I am Joseph Robert, (Joseph named after my Dad's Dad who I never met and Robert after my Dad).

I was born on the 3rd of October 1988 and was the first born child to my parents Robert and Caroline (hence the namesake stuff!).

I was born in Billinge, near Wigan (a pie eater through and through!) and weighed in at 8lb's 9oz. I was healthy, although greedy, hence being taken into special care at 1 day old with dehydration as I was too impatient to be breast fed, once I got the bottle I started to thrive. (and believe you me it's bottle ever since I've needed!)

At the age of 6 months old I was rushed into hospital with meningococcal meningitis. The bugs in my system were so significant it injured my brain in many different places. My Mum describes this like a colander effect all across my brain with probably small lesions all over.

I have worked so hard over the years to try and overcome such a significant brain injury, with much help from my family and friends. I have developed into a happy, smiley teenager, who is known to change into a grizzly bear at some points, an alien at others and apparently other strange beings familiar to families of teenagers all over the land.

I have had a long and sometimes very difficult journey even for my short years. In the early days I was educated at home from the age of 3 for 2 and a half years, I don't remember much

about this only that it was hard work and I learned to walk and read some words. My Mum describes this in more detail in the stuff she has written about this.

I have attended 3 special schools which all have had their good points, but also some very negative ones too. My best memory of school was when I went to the local school (in year 6) where my sister goes (and now my brother). I remember for the first time I had friends and people treated me well, but sadly this didn't last long because the high school wouldn't have me. I don't see these friends any more apart from if I'm out walking with my Mum and Dad, but it isn't me they really say hello to anymore, it's my parents.

I really want to have friends and this is even harder now because I go to a school in Liverpool, this is because it was felt I was too difficult to support in a local special school. This was a special school which I went to after the experience in the local school. It was felt more suitable for me because I would have the opportunity to learn more as the kids there had physical disabilities rather than learning disabilities.

I found this school really hard because it was cluttered, had small class rooms, a lot of the kids used wheelchairs and I just felt like I was in a cage. I really liked my support worker but I needed to move around because I felt trapped. This was difficult for the teachers, support staff and other pupils. I didn't feel really welcome there as many of the staff didn't try to get to know me. This together made me feel more anxious, which made me want to move more, which upset the people around me. It was like a circle going round and round and I wasn't going anywhere. The staff I think got really cross as I was disrupting the lessons. Eventually a big meeting took place and my Mum told me they had had enough and she was looking at another school.

She described it to me as Hobson's choice, I didn't really understand this but she told me it was the name of a book where Hobson really didn't have any choice. So that's it really off they went to look around in Liverpool, the school staff came to look at me (I'm used to that). Then it was decided that money was no object and the education department were paying a lot of money to take me to Liverpool where there were only about 8 of us to begin with. There were some kids I knew though as 3 others were from Wigan. Yes us Wigan lads were all travelling to Liverpool to go to school.

The school is OK and I got Auntie Renee to be my escort again which means bananas, grapes and hoola hoops on the way home.....yipeee.....

The staff are OK but while I have been there staff have changed quite a lot. Many of the kids there struggle a bit like me, but different. I have been hurt by a few of the kids with bites and scratches. We don't have to do things like in the other school and I get to go out quite a bit to the shop and things. They have introduced a different communication system which I can use sometimes but do get stuck using it. I wonder with communication, have they introduced me to this one because it should suit me or them, as the rest of the kids use it.

The school has it's good points but I feel I am not really going anywhere. I need to get out of just existing and start living. Standish and Wigan are really important to me and I think this is where I will live when I am older. I want to be doing things near to where I live and that means school or education or whatever but this needs planning carefully and shouldn't be very sudden.

I have lots of gifts and qualities and want people to see me as a person and not to judge 'the book by its cover'.

I am:-

- Happy
- Friendly
- Energetic
- A people person around people who like me for who I am.
- Someone who loves to laugh with others and have fun.
- A sporty kind of character
- I like to be as independent as possible but understand I need someone with me at all times to facilitate what I want to do and to help me keep safe.
- I hate it when people stop and stare at me, I know I do things which other people don't understand but I want people to know there are things that my body does which I have no control over.
- I need to use my energy productively otherwise I become very agitated and I start to upset people around me by doing things which they deem as inappropriate.
- I like things to be neat and tidy and not for things to be left lying about like keys, the remote control etc.. otherwise I will start to bang on furniture with these things and can't stop doing it.
- I don't use words to communicate but I want to be able to have an effective communication system, I have accessed a variety of different techniques, Facilitated Communication, Picture Exchange Communication System PECS, but struggle with the lack of continuity between the people supporting me. This makes me cross and agitated and sometimes it is easier rebelling against these communication systems because the facilitators don't understand.
- I love going out on my new bike which I have waited years to have my own bike and my Mum finally found a tandem

which I can use with an adult. I was so proud when I did the sponsored bike ride for Wigan and Leigh Scope to Southport with my Dad. People praised me in a way I had never experienced before, like I was doing something for others.

- I don't see myself as having a disability although I know others see me as different. Because I haven't known any different I just get on with it. This doesn't mean though that I like to always be around disabled people, however I must say I don't see anyone as having a disability, just as people really.
- I like to walk our dog Sebastian, he is a Dalmatian and lot's of people stop to stroke him because of this.
- I like music and would love to go to more pop concerts. I try to dance at disco's and like being around other young people. However sometimes music in small areas is difficult to deal with if the noise levels are really unpredictable, like in the car. It also is hard when people are trying to talk at the same time.
- I find it easier in the car with just one other person, with my family or loads of people travelling can be really difficult, particularly if I haven't used up my energy. I can be difficult in the car because I can get agitated and start pulling people's hair, hitting out and nipping. This is because there is too much going on or simply I am bored.
- I love to travel and enjoy holiday's with friends, with lot's of activity in the day and at night. I like outward bound holidays in the lakes, theme parks and also enjoy going abroad so you can swim outdoors. I don't do lying on sun beds because I find it very hard to keep still, although I always get a wonderful tan very easily bobbing about in the pool. My ideal holiday is probably touring, sight seeing with swimming and a good night life. I love America having been to a conference in Syracuse with my Mum and friends, I loved sight seeing in Washington but would

really enjoy going to Florida, However I would have to go with someone willing to support me on the BIG rides cause I love them, my Mum just panics too much and my Dad's not keen.

- I have always gone abroad every year and I have seen many different countries, I would love to see New York, Paris and possibly Egypt and many other cities in this country. However it is getting really hard for my Mum and Dad on holiday because they don't get a break because of my high support needs. Holidays are so important to us all but we have stopped enjoying them because we not interested in the same things. Rosie and Jacob need to enjoy family holidays still, but I want to do different things.
- I also love water sports, but you've got to have the bottle like Clare and Jonny, they took me out behind the speedboat on a ringo when they lived in Spain. I loved it even though my Mum was panicking and constantly checking the risks. With me the riskier the better, this needs working out with my Dad, I'd say he is much cooler about things like this.
- I would love to have more friends. I have some real good one's who have stuck with me over the years, they are a bit older than me but younger than my Mum and Dad. I would like more friends around my own age who treat me as an equal and who I can laugh with.
- I enjoy anything that means going out and about. I will sit and wait at the window if I know your coming for me, the only time when I'm still, my Mum and Dad say! I much prefer being out than in with people who want to be with me and understand me.
- When I want something I do the opposite to what other people do and this confuses people who don't really know me, for instance if you offer me a biscuit I find it hard to take it out of your hand and I will walk in the opposite

direction, I do really want it, put it on a table and I will pick it up when I have accommodated myself in space. (my Mum's words). In other words when I feel safe and OK to pick it up I will.

- I can sometimes trip up and fall over because my co-ordination is poor. I need you to be aware of this as I can get knocked over quite easily.
- I need 2 baths a day at least, one in the morning and one in the afternoon to help me manage my continence and to make sure I don't smell.
- Sleeping is hard for me, I have to be in a room on my own with nothing to stimulate me in the room. I can't sleep with any clothes in the room or clutter or drawers or lamps, wardrobes open etc.. I need you to make the room completely safe and empty. If I can open the door from the inside out I can never get to sleep. I will let you know if I want to come out of the room because I knock, usually within 2 seconds of waking up. I need to go to bed late and I often get up early, it's probably my farming blood! Keep me safe with windows as I knock on them very loudly in particular in a morning or if I am not tired when I am put to bed. I must never have my rings in the room (see later) but I can go to sleep with the TV on timer. You must then very quietly sneak in on me and make sure I am covered up or I will wake up cold.
- I like to be with 'good looking people' and want people to support me to communicate and do other things like this. It is complicated what I mean by 'good looking', my Mum can explain.
- TV and indoor activities are really hard for me, although I do kind of watch TV even though I constantly move around.
- I need at least 1 to 1 support with all my personal care needs. I use continence pads constantly and do try very

hard to use the loo, but again I need a lot of support with this.

- I bang my head with my fist and at times of stress I can do this around 120 times in just 10 minutes. I need help and support to modify this.
- Eating I find difficult on my own I need 1 to 1 support with this.
- Drinking is very hard for me out of a cup or glass, I just can't do it I need a straw or sports bottle, please don't give me a baby cup, but watch cause if I see one I could knick it! I drink juices and pop and only like cold drinks. I won't drink tea or coffee.
- I also have a problem from switching off from drinking. I will drink as much fluid as you give me, people think I am thirsty but I just can't stop.
- Eating fruit or sweets is similar. I will eat sweets with the wrappers on, so watch out at shop counters, Asda is a good place for me to do this as the person I am with is usually distracted. I also will eat bananas with the skin on, by the bunch. This does need controlling by others.
- I have to explain to you about rings and circles. Anything circular like sellotape or hoops or bit's of string or anything similar causes a great problem to me. I can't resist tying things to hoops and circles, in fact when I see anything that resembles a hoop or circle I have got to have it no matter what. I get very anxious if I see a circle or hoop or know it is there, I will go on a frantic search and I can't think of anything else. However when I get the hoop or circle I fixate on it and find it hard to do anything else. Having the circle can sometimes make me calm and helps me to be still, however most of the time it winds me up and makes me very anxious, I also can get very agitated and start to use it as a weapon and hit others with it. Never try and take the hoop off me as I will give you a really hard slap and hurt you. What you

should do is ask me for it and agree when you are going to give it me back, don't make this too complicated, as listening at this negotiation time is hard for me. Always remember I can spot circles and hoops over long distances and can sense if you have spotted one before me. I know at a barbeque there will be plastic rings holding the can's of beer together. Be aware at places like shop counters, stands selling hair bands and bobbles etc.. as I will just grab them and this really worries the people working in shops. This issue has been going on for a long time and nobody can remember when it started, I can go through phases of intensive times. My advice is keep my rings to a moderation and please don't go hunting for them especially for me, avoid them where you possibly can and leave them behind where at all possible.

- My Essential Lifestyle Plan gives far more details and should be added to and up dated as more people get to know me and then hopefully some of the things will develop and change.

IN THE FUTURE

The future is really important to me, all I have ever wanted is the ordinary stuff which for some strange reason others see as extraordinary.

- I need support to help me feel what it is like to be a real teenager.
- I need to find out what type of people suit me best as support people.
- I need to know what it is like to have people in my life supporting me.
- I would like to go to a local college which is meaningful, perhaps when I am 16 so I can meet friends. I like academic work but find the social stuff far more difficult. You will have to work out with me what courses I could access and this would have to be done at my pace, this doesn't mean necessarily simplifying the work though.
- I would like a job and am sure I could find one eventually, I know that I will always need at least 1 to 1 support so I may as well do something useful with my time.
- In the meantime I would like a job to earn some money for myself. I think with help and support I could do a paper round once a week, I could burn off my energy and earn some cash at the same time!
- I also would like to get out more to meet friends and not to be stuck with my sister and brother all of the time.
- I want to go on holiday with friends which could be a cycling holiday, camping and youth hostelling or even going abroad someday.
- Eventually I would like to leave home and would like to live in Standish as I know people round here. I would like to own my own house and earn my own money. I know my sister, brother, cousins and friends will help me to keep this going when my Mum and Dad get too old.

- I need to work all of this out in more detail with my friends and family to help me.

MY PLAN'S FOR NEXT YEAR

Here are some of the things I would like to achieve in the next year:-

- I want to have my own support team to enable me to get a life, make friends and have full access to my communication system.
- To get out more, away from my sister and brother.
- I want to have a clear plan to help me leave school in the summer of 2005. My friends and family must help me to do this. My Mum has suggested we do another PATH with help.
- I want to get active and do things that burn up my energy then I enjoy being at home with my family.
- I want to shop for my own clothes with help from friends.
- I want a little job to earn some money and to be supported to spend it.
- I want to be liked by others.
- I want to learn more.
- I want to do the sponsored bike ride again.
- I would like a holiday.
- I need to start taking some responsibilities from my parents and to prepare for leaving home one day. I want to be supported to tidy my room, change my bed and put my clothes away.
- I want to learn to feed myself this can include meals using a knife, fork or spoon or learning to open a packet of crisps or peel a banana.
- I want to get better at my own personal care and learn how to wash and dry myself with support rather than others having to do everything for me.
- I want to give my Mum and Dad some space and time to do the things they want to do. I know it was really hard for them this Christmas when my Dad was really ill, I

pushed them to the limit which impacts on all of my family.

HOW AM I GOING TO ORGANISE THE HELP I NEED

The kind of people I'd like to support me

I enjoy a variety of people supporting me. I like sporty types with energy who are willing to do things like going out on my bike with me. I like happy people who I can have a laugh with. I like people who genuinely like me and will chat with me even if I am unable to chat back, like in the car. I know the kind of people I like to support me doing certain tasks.

- I want to be with younger people or people who are young at heart.
- I don't want my support to stick out like a 'sore thumb', they need to be friendly and facilitate the things I want to do.
- I want strong people supporting me who won't be intimidated as I grow taller and who can physically support me as I sometimes can fall over.
- I need people with a positive attitude towards me who can handle rude people in the community in a positive way.
- I need people who will get on with my family and who they can trust as they will be coming into our home.
- I will need some male support.
- I need to feel safe and enjoy being with the people who support me.
- I want them to see what is possible and be willing to try new things.
- I want people with their own connections who can introduce me to others and enable me to experience new things.
- I need them to receive a reasonable payment for their support as I will need continuity and I will need people to support me in a very different way from traditional services. I can be very demanding and the work will not

always be easy. I also want to be able to attract male support workers with experience.

The next 18 months will be a critical point in my life as I will be actively going through the transition period as many young people my age. I will be developing the support I need to become more effective and over this time I will become more comfortable and familiar with the support. My income will become enhanced because I will become 16 years old in October and hopefully I will be eligible for Independent Living Fund which will be able to significantly enhance my quality of life.

I have therefore introduced the next 18 months in three phases to try and reflect what my support needs will be.

An Average Week

Phase One

	Morning	Afternoon	Evening
Monday	Help to have a bath, shave get dressed. Breakfast Mum or Dad help.	My Mum and Dad work so meet me from the Taxi. Help after school to get changed, go out for some exercise walking or on my bike and feed me my tea.	At home with family. Mum and Dad put me to bed.

Support hours	1	2	
Tuesday	Help to have a bath, shave, get dressed. Breakfast Mum or Dad help.	Mum and Dad work. Meet me from the taxi after school, get some tea, get my swimming things ready.	Go swimming. Mum and Dad put me to bed.
Support hours	1	2	2
Wednesday	Help to have a bath, shave, get dressed. Breakfast Mum or Dad help.	My Mum and Dad work so Help after school to get changed, go out for some exercise walking or on my bike and feed me my tea.	Duke of Edinburgh Mum and Dad put me to bed
Support hours	1	2	2
Thursday	Help to have a bath, shave, get dressed. Breakfast Mum or Dad help.	My Mum and Dad work so Help after school to get changed, go out for some exercise walking or on my bike and feed me my tea.	Youth Club / paper round Mum and Dad put me to bed
Support hours	1	2	3
Friday	Help to have a	My Mum and	Go to disco or

	bath, shave, get dressed. Breakfast Mum or Dad help.	Dad work so Help after school to get changed, go out for some exercise walking or on my bike and feed me my tea.	out for tea / paper round. Mum and Dad put me to bed
Support hours	1	2	3
Saturday	Help to have a bath, shave, get dressed. Breakfast Mum or Dad help.	Out for a few hours bowling, swimming, bit of shopping, lunch etc..	At home with family Mum and Dad put me to bed
Support hours	1	4	
Sunday	Help to have a bath, shave, get dressed. Breakfast Mum or Dad help.	Young persons parliament group.	Gym / Cycling or a long walk in the Lakes or Rivington. Mum and Dad put me to bed.
Support hours	1	2	3

Total in Hours = 36

Total hours requested per week = 40 to enable Joseph and or his parents to take a weekend break 5 times per year.

The 40 hours will remain consistent during the school holidays.

For 2 weeks each year the total number of hours will increase to enable Joseph to take a weeks break and his family a weeks break. This will mean an additional 256 hours per year to the 40 hours per week. This will accommodate the additional support Joseph will need in his own home as he needs night support at these times.

Phase two

Will be from October 2004 when Joseph turn's 16. The current support will need to be reviewed and enhanced in the summer of 2004 in partnership with the Independent Living Fund so the ILF will be ready to start on Joseph's 16th birthday if possible. The review will look at enhancing the current support in hours and potentially in pay to existing staff.

Phase three

We are to do a PATH very soon in partnership with my circle and other people paid to be in my life like my social worker, school staff etc.. This will look at college and filling my week in a positive way from the summer of 2005. We will need to seek additional funding through further education, learning and skills council etc... The most important part of phase three is to look at my support being as one. This will mean that I have a full up team of support staff who will support me whatever I do at college, at home, on holiday at work etc.. and they will be paid and managed by my trust / family. The team will be flexible in their work patterns so they can have the opportunities to have the good with the not so good. This would provide the much needed continuity in my life as well as ensuring the retention of staff, job satisfaction and happy contented people.

NB: This obviously needs to be worked on now as the funding distribution could significantly change traditional ways of working. Help is needed here as strategically are we ready for this? And experience shows on a local level that further

education needs to readdress it's policies of inclusion that ALL does actually mean ALL.

Specialist Support

- I will need specialist support with my communication.
- I will need specialist support with an Occupational Therapist who can help with my co-ordination.
- I may need additional support at times to help me with any behaviour that I am finding difficult to handle.

To support me well

- You will need training in the way I communicate
- You will need training and an understanding at the way my body functions.
- You will need to recognise any changes in any behaviour and be able to think about if there is anything that will help me.
- You will need to be patient and listen very carefully to how I am expressing myself.
- You will need to explain and tell me what is happening.
- You will need to enjoy my company and be prepared to have fun!

HOW I CONTROL MY OWN LIFE

I understand a lot of what people say and enjoy conversation which is based on facts.

I have a concept of social awareness but find it very difficult to conform to instructions or rules.

I know I need a higher level of support and have always wanted my family to get in control of my support with the view to developing a trust to manage my support in the future.

I want my Mum to act as my agent, which means she will take on the responsibility for managing the details of how my money is spent. I want to be able to review this with my circle as each new phase approaches of my transition.

With my circle we will keep meeting to look at my support and how we can move into forming a trust.

My Mum is my appointee for my DLA and will support me alongside the circle in getting income support and ILF when I turn 16 years old.

How I keep me and other people safe

This has been explored in my Essential Lifestyle Plan which will be constantly updated and reviewed.

How my support is managed

I would like my circle to recruit my staff and my Mum will manage the staff on my behalf.

My Mum will get a local accountancy firm like INSTREAM or NR Barton's and Co to organise PAYE and provide other help about money.

Employers and public liability insurance will be arranged with a competitive broker.

I will have CRB for all staff and this can be accessed through Wigan and Leigh Scope.

We will look at joining a personal assistant employers network or similar to receive support around employment and updating ourselves.

WHAT MY SUPPORT WILL COST

Joseph Budget

	Per week	Per year	Total
Support hours	44.9	2336	
Hourly rate	£8 per hour	£18,688	
Support cost	£359.2		
National Insurance			
Payroll (5%)	£17.96	£933.92	
Insurance (E & PL)		£400	
Travel	£15	£780.00	
Expenses	£10	£520.00	
Specialist Support			
TOTAL	£410.03		£21,321.92

Set up costs		
CRB Clearance enhanced	£100	
Recruitment and contract of employment	£1000	
	£1100	

Total number of hours

Per week 40

2 week holiday break 256

Per Year 2336

Income

Direct Payment	None		
ILF	None		
Services received Over the last year.	Home Care 5 x 2 hours 4pm - 6pm Mon - Fri	Outreach 6.30pm - 9.30pm Thursdays	5 day residential 5 day play scheme in summer

NB

A reassessment was requested in February of 2003 and the process is still ongoing. Additional information is stated in the appendices which was given to Joseph's Social Worker to assist him in his request for additional services to the panel. This still has had no impact on the services that Joseph receives to date.

A question is posed here about why are Joseph's support costs so significant throughout his educational day (£48k plus transport and escort total approx £60k). When his social care costs are so insignificant. Distributing monies evenly throughout Joseph's week would make much more economical sense.