

Testimonials

This booklet contains copies of some of the letters we have received from parents, carers, therapists and consultants who have clients or family members using Helping Hand Company products.

While all text has been faithfully reproduced, some client names may have been changed at the request of the parents or guardian.

June 2019



Intermediate Neuro-Rehabilitation Unit (INRU Ward 3)

Trafford General Hospital
Moorside Road
Davyhulme
M41 5SL

Telephone 0161 934 8660

Fax 0161 934 8661

Trial of Symmetrikit Sleep System on Neurological Rehabilitation Unit

Achievement of consistent 24 hour positioning for neurologically impaired patients can be challenging and complex.

Patients on the neurological rehabilitation unit present with a variable range of complex tonal, alignment and postural issues. A primary goal for these patients is to achieve the best and most comfortable alignment as possible to assist in maintaining good joint positioning and overall postures. This in turn can assist in maintaining outcomes achieved within therapy, as well as allowing patients to rest more appropriately and comfortably.

Historically use of postural management and sleep systems within an inpatient environment has been problematic with staff raising concerns regarding pressure management and infection control.

Recently we have been introduced to a new Symmetrikit sleep system that meets infection control guidance. The Velcro sheets are now single patient use (therefore more cost effective) and all the brackets and adjuncts to the kit can be cleaned and wiped down using standard hospital cleaning equipment.

We have trialed the new assessment kit with 4 patients on the Intermediate Neurological Rehabilitation Unit with very positive results. The patients have ranged in presentation and complexity and the sleep system has been used to offer a range of therapeutic interventions; from maintaining posture and positioning in order to achieve comfort and rest, to being used to increase postural stability and allow increased freedom of upper limb movement and independence.

Patient 1 has significant complex tonal changes, poor posture and a degree of contracture in all 4 limbs. Prior to the introduction of the sleep system she frequently complained of pain and discomfort. Specialised assessment, with very careful, frequent repositioning was necessary to ensure optimal position and comfort was maintained. As soon as the sleep system was introduced the patient reported improved comfort and showed physical signs of improved comfort and stability. This presented as a reduction in global tone and the patient being able to 'switch off' and therefore fall asleep (something which, for her, was previously extremely difficult due to her discomfort).

Patient 2 demonstrated significant issues with fatigue which often lead to deterioration in her posture and position when in bed, therefore maintenance of midline alignment and comfort were difficult. Use of the sleep system has meant that even as the patient fatigues, good posture and alignment can be maintained within the bed, minimising the risk of increased discomfort and the impact this may have on further fatigue.

Patient 3 has significantly reduced postural and core stability and a complex tonal presentation within the upper and lower limbs, impacting on his ability to use his upper limbs selectively and functionally. This results in the patient adopting compensatory movement patterns to aid independence. Use of the sleep system has offered increased core stability and postural support, which in turn has reduced the patients need to use compensatory movement as he is now able to access more appropriate activity. For example, he is now able to feed himself finger foods independently.

Summary

The equipment provided within the kit has been used in a range of different ways and arrangements to provide different support and positioning for each patient. The assessment kit has been found to be very adaptable and can be altered in use to meet individual patient needs.

Use of the Symmetrikit sleep system on the unit has been beneficial in assisting to achieve and maintain good posture and positioning over a 24 hour period as well as offering an adjunct to therapeutic intervention. Management of posture and positioning before biomechanical changes and contracture arise can assist in maintaining therapeutic carryover, optimising rehabilitation outcomes and reducing length of stay. We hope that development of more consistent use of a postural management sleep system, alongside current practices and as part of the 24 hour approach, will be help towards our achievement of this on the INRU.

Susan Bannister
Clinical Lead Physiotherapist
INRU
Trafford General Hospital

John, New Hope Uganda May 2018

John is a 15 year old boy with cerebral palsy. He is wheelchair dependent, tube fed, and unable to move himself. He only has a little active movement in his arms. He needs full care and has lived at a children's centre called New Hope Uganda since he was a young baby. The special needs project "Treasures in Jars of Clay" started in 2009 when Kate Tolhurst, a British special needs teacher, went out to Uganda to care for John. Sadly, in the early years, John's tone and spasms were very difficult to manage, and he has long-term contractures in both his arms and legs. These have got worse over time, and John has also developed a scoliosis of his spine and windsweeping of his hips. For the last 6 months, John has been in a lot of pain, especially with one of his hips.



Unsupported Lying

After sharing John's story with Symmetrisleep, we were very happy to receive a sleep system to try with him. For the first few weeks, we used it for a couple of hours in the afternoons. This meant the care staff could be taught and practice using it, and that John could gradually get used to the new supports and position. Each afternoon, John quickly settled almost going straight to sleep! The care staff could instantly see how relaxed and comfortable he was.



Supported Lying

John has now been using the sleep system every night for nearly a month. The care staff are diligent in using it each night, because they can see the difference it is making. John is sleeping for longer, more comfortably and in much better positions. He is not crying in pain at night. It is still early days, so we don't know if in the long-term there will be improvement in his contractures or scoliosis. But we are thankful that we can now support John in good positions where he is not in pain, and where his body shape is protected. The care staff are now also more aware of John's body position during the day, and we are using some of the cushions to support him when he is in his wheelchair and lying on the sofa.



I am hopeful that the sleep system will not only help John, but also other children in our care, as many have seen and been impacted by the difference that good positioning can make to a child's life. We need to pass this understanding on to parents and other care givers, and to work out simple ways to position children better using local resources. I look forward to seeing this affect the way that we care for all our residential children, and those we support through our special needs school class and in our community.

These are the comments from a few of the staff:

“The sleep system is helping John because his back and legs are not twisting. He is sleeping better and is not crying as much in the day or night.” (R., Care Staff)

“The sleep system is good for John especially when he is lying on his back. He is more relaxed.” (M., Care Staff)

“I am amazed at how easy the sleep system is to use, and how quickly John has got used to it. It has been easy to teach to others, and after only a few nights the care staff are very confident using it. Having seen the positive effects that a good position has on John’s pain, comfort and joints, this is affecting the way he is being cared for not just at night, but also during the day.” (S., Physiotherapist)



Students and Staff

Our thanks to John, Susanna and the staff for sharing this story. If you want to know more about the charities here are the links.

<http://newhopeuganda.org>

<http://www.newhopeugandauk.org/treasuresinjarssofclay/>

Dr. Johanna Rompelberg

Nursing Home in Harrland, Nr Maastricht, Netherlands. April 2012

“The pain medication is significantly lower since we used the dynamic orthosis (Symmetrisleep).”

“If a demand comes in for pain medication, we first look if the lying orthosis (Symmetrisleep) can change and solve the problem.”

“ Muscle Relaxants- we have not used these for a long time since we started using the dynamic orthoses”

From: Tilley Cynthia [<mailto:Cynthia.Tilley@wolvespct.nhs.uk>]

Sent: 13 April 2011 14:33

To: Matt Smith

Subject: RE: sleep system

Dear Matt

I hope this is appropriate;

I issued a sleep system to an eight month old boy. His problems were

- Perinatal hypoxic ischaemia of the brain
- Neonatal seizures
- developmental delay
- and later a diagnosis was made of Severe cerebral palsy asymmetric quadriplegia.

He had severe hypertonia in all four limbs . He had a marked asymmetric posture and a prominent ATNR., plus a strong extension thrust.

The sleep system was incorporated into a 24 hour postural programme .

Currently at the age of four years the child attends a school for severe learning difficulties . He no longer has an ATNR or an extension thrust. He used to sit in a X Panda by R82 and now he just sits in a panda chair. His spine is straight and his hips are intact (covered).

In conclusion I have been very pleased with the sleep system . I feel that by introducing it at such an early age ,it has influenced this little child's symmetrical posture. It is anticipated that he will continue to use the sleep system and hopefully maintain his symmetric posture.

Cynthia Tilley
Senior Children's Physiotherapist

From Charlotte G, March 2019

As a disabled person with multiple health conditions and struggles, I get offered so many solutions and products claiming all sorts of miracles and cures but I must say the CoolOver sheets actually work! I used to suffer every night with night sweats which would keep me awake, not to mention the constant washing of bed clothes and sheets. I could never get the right balance of sheets, blankets and covers to keep me at a regular, comfortable temperature without having hot flushes and sweats. But since trying the CoolOver sheets, I've not had a single night sweat! I never thought that was possible. These are must have items if you suffer from night sweats and over heating at night, and the best part of it is it isn't more medicine and pills. It's a simple, easy solution to the problem and will keep your body temperature at the perfect level all night so you can finally get some uninterrupted and restful sleep. I highly recommend these sheets and thinking about all the nights I've not slept well over the years, I wish I'd started using them years ago.



Kingly Care Partnership
Kingly House 13-19 Mount Road
Hinckley Leicestershire LE10 1AD

Kingly Care Partnership: 01455 613823
Kingly House: 01455 613845
Kingly Lodge: 01455 246 952
Kingly Croft: 01455 246 953
Kingly Terrace: 01536 527180
Fax: 01455 617519

www.kinglycarepartnership.com

Registered Office: 1 Kings Avenue,
London, N21 3NA

Company Number: 5948786. Kingly Care Partnership: T/A
Kingly House

Kay is a 55 year old lady, who has progressive MS. Prior to her admission to Kingly Care Partnership she had been totally bed bound for a period of 18 months as a result of significant postural deterioration due to alterations in muscle tone, contractures and previous hip fracture. She lay in a position of significant lateral flexion, kyphosis, rotation, fixed flexion of one leg and extension of the other which resulted in her legs being rigidly crossed and contracted into an oblique position. On admission to Kingly Care Partnership and following immediate assessment, it became clear that this physical fixed position had extensive impact on Kay's level of pain and discomfort, ability to functionally engage due to limited movement of the upper limbs and an inability to gain a seated position. It also made meeting Kay's needs in regards to personal hygiene and pressure management extremely challenging. Kay struggled to tolerate regular physiotherapy due to her mental health needs and therefore it was considered that a sleep system may be more appropriate. A Symmetrikit system was provided to be used by individually trained rehab support workers and overseen on a daily basis by the OT team.

Kay has now been using her sleep system for just over 1 year and the positive impact has been notable and remarkable. She is no longer restrained by her fixed and ridged body positioning; meaning that her natural supine position is far more aligned, supported by more normal muscle tone and a significant reduction in enduring discomfort. She is able to manoeuvre her own body position when in lying to some degree and has regained functional use of her right arm, over the last 12 months, which was previously trapped by her body's position, allowing her to eat and drink independently and participate in painting which she has always enjoyed.

She has gained enough passive movement to be able to achieve a seated position and as such is able to sit in a custom moulded

wheelchair. This means that she is no longer bed bound and can now engage in a more normalised daily routine, dictated by her own choices; which include regular visits to her family's homes, going out to shop and for her favourite costa coffee. Her lower limbs no longer cross allowing for personal hygiene to be far more easily maintained and previously vulnerable areas of skin no longer have any issues. Recently Kay's movement was noted to have improved so much that a review of the sleep system took place and level of support in place has been reduced with a new goal set to work on ankle movement. It is clear that alongside a full range of therapeutic approaches to manage Kay's global needs the Symmetrikit has been a key and essential aspect of her physical rehabilitation.

May 2012 From Bev Kelly, Occupational Therapist.

Helping Hand Company

Symmetrisleep Review- An OT's experience

I am a state registered Occupational Therapist with 23 years post-registration experience in Health, Social Services and the Independent sector. I run my own business alongside another Occupational Therapist, providing Occupational Therapy, a shop selling disability equipment and adaptations.

My client, whom I shall name Barbara for the purpose of this review, suffers from chronic osteoarthritis affecting her spine, hips and knees. Orthopaedic surgery had been ruled out a few years previous due to other complicating medical problems. Barbara also has dementia and a left sided weakness following a stroke. As a result of these problems, Barbara had been bed bound for a number of months prior to my initial assessment. She had developed severe flexion contractures around the hips and knees and was experiencing pressure related problems on her foot and bottom. Her legs were severely adducted making personal care and dressing very difficult. Barbara was unable to sit in a standard chair or wheelchair and as a result her ability to socialize or participate in activity was non-existent.

Barbara was being cared for in a Nursing home on a profiling bed with air mattress. Positioning in bed was inconsistent and made difficult by Barbara's need to pull herself over onto her left side using the bedrails required to ensure she stayed in bed. Additional pillows and a bolster were being used in an attempt to position Barbara in bed.

Barbara's family wanted to improve her comfort and quality of life. Consideration of seating, mobility and support in bed were made.

Our aim was to identify a system which would allow Barbara to be positioned on her back and both sides. This also needed to maintain a high level of pressure relief and be suitable for us to implement within a nursing home setting.

A demonstration of the Symmetrisleep system was arranged with our rep Matt Smith, at a time to suit the client, Therapists and Nursing staff at the care home. Our first impression was positive. The system aims to increase the base of support thus decreasing the risk to specific pressure points and reducing tone. It gently maintains the body in, ideally, a symmetrical position reducing stress on specific joints and is made of materials which wick away excess moisture and help to maintain a constant body temperature. Barbara's initial response to the equipment was positive. Her tone decreased and she appeared much more relaxed, no longer reaching for support. Matt demonstrated how the elements of the system could be tailored to meet Barbara's specific needs and could be developed to offer not only a positioning aid but a therapeutic tool.

As a result of the positive response we had gained from Barbara on the demonstration it was agreed that the Symmetrisleep system offered the level of support and ease of use that we had wanted. Matt agreed to provide support on handover of the product along with training on the use of the equipment with the staff at the nursing home. The equipment was ordered and staff training given at handover and a further session to incorporate night staff.

As a result of the Symmetrisleep system and its careful implementation Barbara is now experiencing a much better quality of life. She is repositioned appropriately in bed which is decreasing her tone and preventing further flexion contracture. All her pressure areas are healed. As a result of this Barbara is able to attend hydrotherapy where we have been able to encourage further stretch and extension. More importantly, Barbara can exert some control over her movement and environment when in the water. The tone in her legs has decreased making it easier for Barbara to be seated in a tilt in space armchair or wheelchair and making dressing and personal hygiene easier for the carers to manage.

From the experience I have had in working with Helping Hand in the provision of the Symmetrisleep system and witnessing the positive effect it has had on Barbara's life, this equipment will certainly be considered as an effective option for the positioning of my future clients.

Craig

Friday 30th January

Craig went to bed at approx. 12.00am.

He was asleep by 12.30am and slept until 10.30am

Saturday 31st January

Craig went to bed at approx 11.30pm.

He was asleep by 12.00am and slept through until 09.00am

Sunday 1st February

Craig went to bed at approx 11.30pm.

He was asleep by 12.15am and slept through until 07.45am

Monday 2nd February

Craig went to bed at approx 11.00pm.

He was asleep by 11.30pm and slept through until 07.45am

Tuesday 3rd February

Craig went to bed at approx 11.00am.

He was asleep by 12.00am and slept through until 07.45am

Wednesday 4th February

Craig went to bed at approx 11.30am.

He was asleep by 12.15am and slept through until 07.45am

Thursday 5th February

Craig went to bed at approx 11.30pm.

He was asleep by 12.00am and slept through until 07.45am

Friday 6th February

Craig went to bed at approx 11.30pm.

He was asleep by 12.15am and slept through until 10.30am

(Craig's mother wrote to us to advise of his new sleep pattern while using the Symmetrisleep System. Prior to using the kit, Craig would normally have woken 3 or 4 times per night. A report of his sleeping pattern can be found on the next page. Craig was 19years old at the time of this letter, suffers from CP and lives in the Northwest..)

CRAIG cont..

'Craigs sleeping pattern before trying the Symmetrisleep system was practically non-existent. I would try to get him to bed between 10.30pm and 12.00am but he wouldn't go to sleep – sometimes not until 03.00am or even later. When it came to getting him up for school it was a job in itself! He would be falling asleep in his chair and wouldn't eat his breakfast. Sometimes even being sick after a couple of nights without sleep. He would spend all morning at school, asleep, which isn't very practical.

Since trying the Symmetrisleep System – what a transformation. Most nights asleep within $\frac{3}{4}$ hour of going to bed. He's awake on a morning for school. He can have his breakfast and he's enjoying school more. He's brighter, happier, more alert. His change was noticed at school and happily relayed to me with much enthusiasm.'

CHRISTOPHER 6 years old – PRESTON 1998

'...He has never slept particularly well, but since he had an operation to stretch his tendons and hamstrings two years ago, he has found it impossible to settle in a comfortable position to sleep in bed. During the last two years we have tried many ways to help Christopher get comfy in bed – padding, splints, legs together, legs apart, sitting, lying etc.. and nothing has helped him get more than half a night's sleep without him being moved to his pram for the remainder of the night – if he could get to sleep again. This has meant that Christopher has been tired and grumpy during the day...

...since Christopher has had a Symmetrisleep he has slept at least eight or nine hours per night and has to be woken during the week for school!..he is usually happy when he wakes (as opposed to immediately crying as soon as he opens his eyes) and is much more cheerful during the day as at last, he is getting enough sleep – and so are we!

letter received from Senior Physiotherapist based at the Day Centre after trials of Sleep System with three clients.

...'We have been using the Symmetrikit bed for three of our clients for some months.

Client 1

This client used to wake at least six times a night asking to be moved or toileted and now she sleeps all night with her posture much improved.

Client 2

This client was waking in the morning with her feet resting against her spine in an extreme windswept position. Now with the Sleep System her posture is becoming much straighter and the foot box on her wheelchair has been moved in six inches to mid line from it's lateral position

Client 3

This client has extreme extensor spasms and scissoring of the legs. With the Sleep System a much more relaxed position has been obtained with some reduction in scissoring – this still needs more work.

Overall, for these clients with severe deformity, using the Sleep System we have obtained good postural correction and hope for more – giving the clients a better quality of life – and finally reduced the workload of the carers who find it very user-friendly. Thank you Symmetrikit – from all sides..'

KATIE 16 years old – 1998

“Dear Symmetrikit,

Just a few lines to thank you for a remarkable new product – your new Sleep System. I am a Mum of a 16 year old Cerebral Palsy child with severe hip and back problems. Up until now she has been sleeping on a Spenco mattress with no support, in the most terrible position.

Now, thanks to your new sleep system she has been sleeping peacefully, comfortably and totally supported in a near perfect position which we have not seen her in for the last 10 years. Katie is also much happier on waking and so much more supple to handle and position in her special seating mould.

The Sleep System is on loan at the moment and I am looking forward to purchasing one from you in the near future.

Also, a lovely comfortable chair as well. Thank you very much!...”

DAVID – Yorkshire 1997

‘..I am writing to let you know how my son David got on using the Sleep System you lent me for a trial period. As I explained to you when we met, David’s sleeping pattern was that he was put to bed at 9.00pm and kept awake until midnight. Then he would wake at 02.30am and go back to sleep at 03.30am, and wake up again at 06.00am.

During the times he is awake someone has to be with him or he will not go back to sleep at all. After you called and fitted the Sleep System I put David to bed as usual at 9.00pm and ten minutes later he was fast asleep. He stayed that way until 06.00am.

David slept like that for the whole 10 days that we had the Sleep System and I would recommend that people try it to see if it could work for them.

Now the Sleep System has gone, his sleeping pattern has reverted back to what it used to be but we are now waiting to see if we can be supplied with one on a permanent basis because it not only helped David, but the rest of the family too..!’

JANUARY 1998 – Client name not given

‘...may I also take this opportunity to tell you what a huge difference your product has made to the life – or should I say night! – of my son. It is very ingenious, yet simple. Thank you...’

SAM 9years old – 2000

‘Sam used to have a terrible nights’ sleep. His body would be locked in a foetal position and he would constantly wake up due to cramps. Sam’s tone would be terrible in the morning – very tight and stiff.

When sitting, he would constantly lean to the side, wouldn’t be able to feed properly due to increased tone in his shoulders.

If Sam was drawing he knew what he wanted but it would just be a scribble as his fine motor skills were terrible...

...This bed has made quite dramatic changes to Sam. He sleeps straight and with his arms down so is much more relaxed in the morning. His Physio at school has noticed the change in his tone and is very pleased. When sitting, his posture is much better and straight.

He is using his cutlery much more efficiently and his penmanship is coming on in leaps and bounds. Sam has taken to the bed really well and doesn’t mind being in one position with his legs strapped. The only thing I can find fault with is that it makes him sweat terribly.

It is a fantastic invention!’

(New AIRSHEET available to provide thermal comfort and prevent sweating)



Sam is delighted that he is now able to draw a ‘Big-nosed man’!

HANNAH 11 AND ½ 2001

I AM HANNAH. I AM IN A WHEELCHAIR AND HAVE GOT CEREBAL PALSY. I'VE USED THE SLEEPING SYSTEM FOR A COUPLE OF YEARS AND HAVE GOT AN AWFUL LOT OUT OF IT, WHICH IS WHY I HAVE WRITTEN TO YOU TO TELL YOU ABOUT IT. IT IS QUITE STRANGE AT FIRST, BUT I GOT USED TO IT WITHIN A COUPLE OF NIGHTS. IT IS EXTREMELY COMFORTABLE, I SLEEP RIGHT THROUGH THE NIGHT NOW. I HAD IT BECAUSE WHEN I WOKE UP I COULD NOT WEIGHTBEAR VERY MUCH AND MY LEGS WERE CROSSED. NOW I HAVE GOT IT I FEEL MUCH MORE ABLE TO TAKE WEIGHT WHEN I GET UP. I ACTUALLY PREFER TO TAKE IT WITH ME WHEN I AM HAVING A NIGHT AWAY FROM HOME . I ALSO TAKE IT WITH ME ON HOLIDAY. I DON'T EVER THINK I COULD GET USED TO NOT SLEEPING WITH IT AGAIN. IT IS A GREAT SUCCESS.

JESSICA 9 YEARS OLD

OUR DAUGHTER JESSICA WHO IS NINE YEARS OLD WITH SEVERE CEREBAL PALSY HAS BEEN USING HER SLEEP SYSTEM FOR JUST OVER ONE YEAR NOW WITH VERY PLEASING RESULTS. Having had slight reservations at the start as to whether it was something she would tolerate we feel now it has made a real difference to her posture.

Before we had the system she used to sleep curled up on her side waking up very stiff in the morning. She was also starting to have problems with her hips and scissoring legs. But now she sleeps in a very straight a-lined position which she feels secure in (this is important as she is also visually impaired) all nights.

At her recent year's x-ray at g.o.s. it showed that her hips are now very stable with a slight improvement which is good news for jess.

NICOLA'S SON – PORTSMOUTH – SEPTEMBER 2004

My son has just received his sleep system I really don't know how we have managed without it, he is 8yrs old and for the last 3 weeks he has slept all night everynight, up until then we had not had a full nights sleep since birth, his positioning day and night are very complicated and needed lots of different appliances to achieve this but this is so simple it has changed our lives, Nicola

VRANCH HOUSE SCHOOL – EXETER (MARCH 1998)

Dear Sir,

...'I would be grateful to receive the order here at Vbranch House School as soon as it is possible so that I can introduce another family to the enormous benefits of your sleep system. Jodie's and her families' nights have been transformed by the system I have lent them. She is sleeping through most nights instead of needing attention up to seven times a night. There are also spin-offs in the day. The spasticity in her legs is reduced, she is more relaxed and straight. Because of the better sleeping she is also less sleepy in the day, joining in groups and activities with more enthusiasm. We are gathering evidence like this so hopefully we will be able to secure funding for other families..'

(this letter was written by a Physiotherapist working at Vbranch House School)

45 Leicester Road
QUORN
Leics.
LE12 6BA

21 May 2010

For the attention of Mrs Sue Forrest

Dear Sue

Re: Symmetri Sleep System

I would like to thank you for obtaining the above sleep system for my son Nicolas Gaskin. Until he used this system he suffered from back pain caused by the misalignment of his legs due to tendon/muscle tightening. The system works by gently straightening and supporting his legs and removes adverse pressure on his spine and internal organs. Even though this system seemed complex at first, all Nick's carers, including agency staff, have no difficulty in placing it correctly due to a series of photographs on his wall which explain it step by step.

Nick regularly attended hospital for botulinum injections in his legs. These are no longer necessary and his Neurologist was so interested he asked for a picture of Nick using the system.

It has made a tremendous difference to his quality of life and we are very grateful.

Yours sincerely



Mrs P S Jenczyk

My thoughts about the sleep system:

The sleep system has made a huge improvement for Mateo.

- Mateo's head doesn't hook as much, which is a massive improvement.
- When we first position him in the sleep system he is lovely and straight and only needs repositioning a couple of times through the night.
- His legs don't scissor, and he doesn't twist as much.
- I like being able to pull the sheet to re position him, as it is far easier and doesn't disturb Mateo.
- Mateo is comfy in the sleep system even though he has a knee block and lots of pads securing him.

25th January 2011

Sleep-System Anecdote

Anna is a ten year old girl who has a diagnosis of spastic cerebral palsy affecting all four limbs. Anna was assessed and provided with a sleep system in 2001 at the age of one.

At the beginning of 2010 Anna developed a pressure sore on her ankle which was treated by nursing staff but had still not healed several months later. An air-flow pressure mattress was then recommended by the nursing staff to aid the healing.

I assumed the sleep system could not be used on an air-flow mattress, so the sleep system was removed and the air mattress was used instead. Anna had been using the sleep system for many years and her mum was happy to use it, but as Anna had used the system from such an early age her mum was unclear of the benefits, it had simply become part of their routine.

Anna's mum contacted me a couple of days after the sleep system was removed asking if it could be put back in as she was struggling with Anna's care. Mum reported that Anna's legs were stiffer in the morning making it more difficult to roll her for changing, dressing and inserting her hoist sling. Mum also reported that Anna was reluctant to be touched on her pelvis and she showed facial expressions of pain when touched in this area.

When the air-flow mattress was removed approximately two weeks later and the sleep system re-positioned, Anna was immediately easier to manage in the mornings and her mum is now more aware of the benefits and the reasons why the sleep system should be used.

I hope this is useful to you.

Lydia Bazeley
Children's Occupational Therapist

01772 644539



South West Essex Community Services

Children's Occupational Therapy Service

John Tallack Centre

Thurrock Hospital

Long Lane

Grays

Essex

RM16 2PX

Tel; (01375) 364554

Fax; (01375) 364620

Dear Adrian

Just a quick note regarding the sleep system we used to help position Kudzai (12 years old) at night times. As you know she is an incredibly complex child with cerebral palsy – spastic quadriplegia. She found night times very uncomfortable as the changes in her tonal patterns enabled her to get into positions that were not ideal for her pelvic and trunk alignment. We also had the issue of orthopaedic surgery which meant that her left leg was able to actively move in different ways to her right meaning that we almost needed two different sleeping positions.

Having worked with the symmetrisleep system and yourself for a number of years I was confident that you would come up with a solution to the problem. We were able to devise a supportive sleeping position which firstly dealt with the postural asymmetry following surgery but was then able to encourage a more supportive and symmetrical sleeping position a few months later.

The impact on Kudzai's life has been dramatic. This system is used as part of our 24 hour approach to her postural management, good alignment and support at night is helping to maintain the range in her hips. The improved hip position is preventing her from becoming twisted in her trunk which enables her to bring her arms and hands down by her side when she relaxes and sleeps instead of up and around her head. She now has a decreased risk of contractures and hip dislocations and the overall picture is a happy, energetic young lady throughout the day.

Excellent outcome to a challenging situation!

Aaron Preston BSc OT
Advanced Occupational Therapist

Managing Director: Jackie Brown, Chair: Frances Pennell-Buck.
NHS South West Essex Community Services, Suite One, Phoenix House,
Christopher Martin Road, Basildon, Essex, SS14 3EZ.

Telephone: 01268 244600, Fax: 01268 244601

www.swessex.nhs.uk NHS South West Essex Community Services is
hosted by South West Essex Primary Care Trust (NHS South West