Edition THREE : August 2010

NHS
SCOTLAND

BETTER HEALTH, BETTER CARE
update

on the National Delivery Plan for Children and Young People's Specialist Services in Scotland

healthier scotland
SCOTTISH GOVERNMENT

WELCOME

I AM DELIGHTED TO WELCOME YOU TO THE THIRD EDITION OF THE SPECIALIST CHILDREN'S SERVICES NEWSLETTER.

May I start by saying how encouraged I am to see the real progress and improvements being made to services as a result of the investment. I am tremendously pleased to see how monies are being used to offer children more comprehensive care, such as dedicated dietetic support and physiotherapy, which will no doubt improve their quality of life.

It is also encouraging that expertise is being used to upskill colleagues, helping ensure sustainability of service rather than depending on a small number of individuals. The work being done to create educational resources is very positive and will, I hope, continue to raise the standards of care offered to this vulnerable patient group. Providing information for families is also an important element of the overall care package, and one which I am sure is much appreciated as parents come to terms with their child's condition. All this points to a more holistic approach to care, looking beyond the medical treatment to an all-round approach, including the psychological effects of living with a specialist condition through childhood.

Many examples are evident of how care is being brought closer to home, and of how much this is appreciated by patients and their families. Comments such as those on page 10 are hearty endorsement of this move towards outreach, and of the increased use of telemedicine.

In the current climate of financial restraints and accompanying workforce challenges, it is reassuring to see evidence of Boards adopting pragmatic and innovative approaches, such as using Advanced Practitioners to take on additional responsibilities (page 7). This not only relieves pressures on colleagues and allows better workforce deployment, but also provides a motivating career pathway for those who broaden their skills.

We continue to set ourselves ambitious targets, such as a 30% reduction of adverse events in paediatric treatment by 2013. I appreciate that the continual improvement of service is a challenge, but am in no doubt of the dedication of all those in the field to making sure this happens.

Finally, I would like to thank all those who have dedicated their time and effort to translating the commitments made in the National Delivery Plan into action. As the articles in this newsletter show, your continued efforts are having very real effects on the ground, and I look forward to watching progress in the coming year and beyond.

Nicola Sturgeon

NICOLA STURGEON
Cabinet Secretary for Health and Wellbeing

TELEMEDICINE: the value of remote assistance

HAZEL ARCHER, TELEMEDICINE PROJECT MANAGER

THE MANAGEMENT OF SPASTICITY IN CHILDREN WITH SEVERE CEREBRAL PALSY IS CHALLENGING. IMPROVEMENTS IN MUSCLE TONE AND CONTRACTIONS CAN LEAD TO SIGNIFICANT IMPROVEMENTS IN THE QUALITY OF LIFE FOR BOTH CHILDREN AND THEIR FAMILIES OR CARERS. BACLOFEN IS THE DRUG COMMONLY USED TO CONTROL THESE SYMPTOMS AND, IF GIVEN DIRECTLY INTO THE SPINAL CORD, IT CAN WORK EFFECTIVELY AND WITHOUT SIDE-EFFECTS.

To administer the drug directly into the nervous system a complicated procedure is needed where a small pump is implanted into the abdominal wall, in a similar way to a pacemaker device. This pump needs to be reprogrammed and refilled from time to time but the correct programming and dosing is critical. There is no room for error.

Altering the settings and adjusting the dose on the pump does not require further surgery or any other invasive procedure. It is a simple and quick process whereby a small Bluetooth enabled external control is placed on the patient's skin, to transmit data directly to the pump.

Consider the plight of Adam and his family who live in an island setting where the nearest paediatric neurology unit is hundreds of miles away. For them to attend an urban clinic, just for the 5 minutes it takes to complete the procedure requires 2 days of travel, time off work and finding alternative child care for Adam's little sister. The cost of travel, meals and accommodation is considerable too. The alternative is to ask the consultant to travel and see Adam to carry out one short clinical procedure before catching the plane back to the city, weather permitting. Is this the best use of a scarce clinical resource?

Dr Martin Kirkpatrick, Chair of the North Scotland Child Neurology Network (NESCANN) and a consultant at Tayside Children's Hospital, thought there was an alternative to the above scenario. Using the Tayside Paediatric Telemedicine service, supported through NDP funding, he was able to remotely guide and mentor a local GP in Orkney to successfully (and safely) change the settings on the pump. This first known attempt in using telemedicine for such a procedure took less than 30 minutes in total, saved thousands of pounds and, perhaps more importantly, caused minimal disturbance to Adam's life and that of his family.

He said: "The paediatric telemedicine service is fast becoming an essential tool in the operation of a specialist service whose remit is to cover the huge geographical areas that exist in the north of Scotland."

MIND OVER MATTER:
training paediatric staff to help children and young people cope with the psychological impact of their condition

TERRI CARNEY, NES PROGRAMME DIRECTOR (PSYCHOLOGY)

THE NATIONAL DELIVERY PLAN (NDP) RECOGNISES THAT PSYCHOLOGICAL CARE IS A KEY COMPONENT IN PROVIDING A QUALITY HEALTH SERVICE. CHILDREN AND YOUNG PEOPLE WITH ACUTE OR LONG-TERM PHYSICAL HEALTH CONDITIONS ARE MORE VULNERABLE TO DEVELOPING MENTAL HEALTH OR BEHAVIOURAL PROBLEMS THAN THOSE IN GOOD HEALTH. ALTHOUGH THERE IS A GREATER RISK, MANY CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES ONLY REQUIRE PSYCHOLOGICAL SUPPORT AT SPECIFIC TIMES (FOR EXAMPLE, ADJUSTMENT TO DIAGNOSIS, DEVELOPMENTAL TRANSITIONS, EXACERBATION OF SYMPTOMS, COMPLEX TREATMENT REGIMENS) OR FOR SPECIFIC FACTORS (FOR EXAMPLE, MOOD DISORDER, PAIN MANAGEMENT, NON-ADHERENCE).

All healthcare staff working in Specialist Children's Services require to be psychologically minded and anticipate the emotional challenges faced by children, young people and their families. This in turn forms the basis of effective assessment and intervention at the required level of care. Several studies have shown that good quality psychological care reduces psychological distress, improves coping and enhances the quality and effectiveness of medical care.

Funding from the NDP has enabled NHS Education for Scotland (NES) to appoint a Clinical Psychologist to develop educational resources aimed at upskilling staff working within Specialist Children's Services on psychosocial aspects of care. This work will focus on key areas of difficulty which are common to all physical health conditions and are known to respond well to effective support and intervention. These include adjustment to diagnosis, adherence to treatment and self-management. Many staff will have considerable skill and experience which can be further developed to optimise competency and confidence in meeting best practice standards. The aim is to have resources developed by September 2010 and present the draft to a large group of stakeholders to inform the final outcome. Following this a cascade system of delivery including initial training for trainers and then local training for multidisciplinary staff in the North, West and East of Scotland will be undertaken and evaluated. This will enable sustainability of educational provision and consistency of care. It is envisaged that for children, young people and their families the result will be improved recognition of psychological challenges, appropriate intervention and the experience of participating fully in a culture of accessible psychological care. For evidence of the value of applied psychology see page 20.

PAEDIATRIC PATIENT SAFETY PROGRAMME

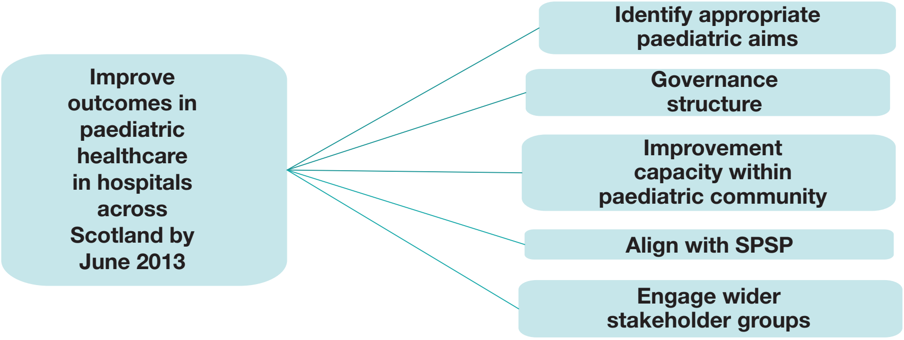
JULIE ADAMS
NATIONAL FACILITATOR

THE NATIONAL FACILITATOR FOR PAEDIATRICS WITHIN THE SCOTTISH PATIENT SAFETY PROGRAMME IS A ROLE THAT HAS BEEN FUNDED BY NATIONAL DELIVERY PLAN MONIES TO SUPPORT THE DEVELOPMENT OF A SPECIFIC PAEDIATRIC PROGRAMME TO SUPPLEMENT THE ALREADY ESTABLISHED SCOTTISH PATIENT SAFETY PROGRAMME (SPSP).

SPSP began in 2008 and is almost half way through this 5-year programme. The aim is to improve hospital care across Scotland by using evidence-based tools and techniques to improve the reliability and safety of everyday healthcare systems and processes. Improvement has been shown in a number of areas within the programme, e.g. a significant number of adult intensive care units have gone more than 300 days without a central venous catheter bloodstream infection. It was due to the successes demonstrated in the workstreams of SPSP i.e. critical care, general wards, leadership, medicines management and peri-operative care, that the plan to accelerate the programme into paediatrics was developed. Approval was given by the National Advisory Board who oversee the Scottish Patient Safety Programme and a funding application was submitted to the National Delivery Plan to support this development within paediatrics.

The National Facilitator for Paediatrics is a 2-year secondment designed to support the development of a specific patient safety programme for paediatric services. Since beginning the post in November 2009, the emphasis of this role has been to develop the aims, goals and measures of the Scottish Patient Safety Paediatric Programme. It has been developed using the same infrastructure as the adult programme with five workstreams. But recognising that children aren't little adults, the aims have been based on areas relevant to paediatric healthcare, and designed to recognise the unique configuration of Scotland's paediatric services.

The driver diagram opposite depicts the areas for improvement that support the overarching aim of improving outcomes in paediatric healthcare within the Scottish Patient Safety Paediatric Programme. This lays out the areas that the Paediatric Programme will focus on to ensure the delivery of the overarching aim; so it is not only addressing the development of appropriate paediatric aims, but also ensuring that paediatric staff are trained to deliver an improvement programme and that the programme sits within an appropriate structure.



PAEDIATRIC PATIENT SAFETY PROGRAMME CONTINUED

A launch event was held on 16 and 17 June, where over 110 paediatric nurses, doctors and pharmacists attended from 12 NHS Boards. The aim of the paediatric programme is to reduce adverse events by 30% by June 2013, by ensuring that reliable systems are in place that can measure the application of best practice and continually monitor and improve outcomes. Key areas within this programme are to improve the recognition of the deteriorating child and to ensure reliable care planning, communication structures and the collaboration of multi-disciplinary teams, vital in all areas of specialist and non-specialist paediatrics.

The launch event was also aimed at developing the capacity within the paediatric workforce to implement this improvement programme, show staff how to use the model for improvement and empower them to start developing their own local small tests of change that will drive the larger aims of the programme forward.

The National Facilitator's role within the Scottish Patient Safety Programme not only supports specialist children's services, but will also facilitate learning and collaboration across paediatric wards across the whole of Scotland, to improve measureable outcomes in paediatric care.

PONSETI MANAGEMENT OF CLUBFOOT –
A Physiotherapy-led Service: the case for Advanced Practitioners

SARAH PATERSON, ORTHOPAEDIC EXTENDED SCOPE PRACTITIONER

ROYAL HOSPITAL FOR SICK CHILDREN, EDINBURGH

IN NOVEMBER 2008 AN ADVANCED PAEDIATRIC PHYSIOTHERAPIST WAS EMPLOYED THROUGH WAITING LIST INITIATIVE MONIES TO INTRODUCE THE PONSETI TECHNIQUE FOR THE MANAGEMENT OF BABIES BORN WITH CONGENITAL TALIPES EQUINOVARUS (CTEV)/ CLUBFOOT AT THE ROYAL HOSPITAL FOR SICK CHILDREN, EDINBURGH. THIS WAS A RADICAL CHANGE IN THE MANAGEMENT AWAY FROM INVASIVE SURGERY TO A CONSERVATIVE TECHNIQUE THAT HAS BEEN PROVED TO BE 95% SUCCESSFUL OVER THE LAST 50 YEARS.

In 2004 it was identified that there was a need to change the approach and management of babies born with CTEV. At this time parents were beginning to learn of the Ponseti technique and were requesting it for their babies. The Ponseti technique was being used successfully in Kirkcaldy, Perth and Glasgow by orthopaedic consultants at this time. It was initially identified that a skilled physiotherapist could, at the least, be involved in the delivery of this service. A financial business plan showed that the decreased theatre time, surgeon time and overnight hospital stays afforded by this technique would make it cost neutral. It also showed that there would be a reduction in waiting times for orthopaedic outpatient appointments and those requiring surgery, due to freeing up of consultant time. A paper produced by The Royal Free Hospital and Great Ormond Street in 2006 which described the results of a physiotherapy delivered Ponseti service was used as a model. The study showed that the results from a physiotherapy delivered service could equal those obtained and reported by medically trained personnel. At this point it was proposed that an advanced physiotherapist could deliver this service.

The vision for the service was to be led, not just delivered, by a physiotherapist. In order for this to happen the physiotherapist needed to be able to make an initial diagnosis and to screen for other complications. They needed to be able to independently progress treatment and be able to modify this when complications arose. They needed to be able to identify early when complications or relapses occurred. Finally, they needed to be able to make decisions on need and timing of surgery as well as request and analyse radiology. The physiotherapist therefore needed to be experienced and advanced in their practice.

PONSETI MANAGEMENT OF CLUBFOOT CONTINUED

Funding for this post was approved in August 2008 and the physiotherapist came into post in November 2008. There were some initial hurdles to the establishment of the service. These included historical opinions on roles and definitions between medical and physiotherapy roles and abilities, reluctance by some to change to a new technique and lack of suitable accommodation in which to hold the clinics.

So far over 50 babies have been treated since the physiotherapist was appointed, with a 100% success rate for those compliant with treatment (only 2 cases of poor compliance). No children have required invasive surgery. Parent satisfaction so far has also been encouraging. The service has now developed to offer ante-natal counselling to parents which can dramatically reduce parental shock and anxiety at the time of birth. A parent support group has also been developed which can be hugely beneficial in ensuring compliance with the regime and reduced parental anxiety. Through a recycling campaign of boots and bars, organised by parents, CTEV patients in the third world are now benefiting from improved equipment and, consequently, a far better chance of successful treatment.

In 2010 the physiotherapist running the Ponseti programme was accepted onto the NES Advanced Practitioner Development Pathway and received a grant of £2,000 towards education. This has been used to send the physiotherapist to the Iowa Children’s Hospital, USA for 2 weeks to learn from the world’s leading experts in the Ponseti technique.

The service can now offer expert care for the management of children with CTEV by one practitioner. It can also offer advanced skills in the manipulation and application of plaster casts along with early intervention in the event of problems/relapse. There is now also a robust training programme to ensure the continuity of the service and succession planning.

The future plans for the service include training the physiotherapist to perform Achilles tenotomies, expansion of current audit to help refine treatment and support strategies, gait analysis at age 5 years and a parent satisfaction survey.

Improving respiratory physiotherapy services to children with complex respiratory illness throughout South East and Tayside (SEAT)

ELAINE DHOUIEB, PHYSIOTHERAPY RESPIRATORY CLINICAL LEAD AND ZOE SELL, SPECIALIST RESPIRATORY COMMUNITY PHYSIOTHERAPIST

PRIOR TO 2007 THERE WERE 2.4 WTE PHYSIOTHERAPISTS COVERING RESPIRATORY IN- AND OUT-PATIENTS IN RHSC EDINBURGH INCLUDING PAEDIATRIC INTENSIVE CARE (PICU) AND THE REGIONAL CYSTIC FIBROSIS (CF) SERVICE. PATIENTS IN OTHER AREAS OF SEAT WERE SEEN AS IN-PATIENTS BY ADULT RESPIRATORY PHYSIOTHERAPISTS OR GENERAL PAEDIATRIC COMMUNITY PHYSIOTHERAPISTS.

In 2007 NSD funding was obtained for 2 wte PICU staff to bring staffing in line with other specialist units nationally. In 2009 NDP funding provided 2 wte at RHSC, 0.5 wte in Borders, Fife and 1 wte in Forth Valley.

This is already providing better quality, more coordinated and expert care to in-patients, community patients and out-patients with complex respiratory problems including CF.

The main benefits and aims of the service are:

- Delivery of consistent, sustainable, child-centred, evidence-based care as locally as possible
- Improved patient and carer satisfaction and confidence to manage long-term respiratory conditions
- Increased CF outreach clinics in Forth Valley, Fife and West Lothian with the RHSC MDT team working alongside local staff providing care closer to home
- Provision of specialist paediatric respiratory care in District General Paediatric Wards with shared competencies and guidelines to prevent admission to RHSC and allow in-patient care locally
- Continuity of care for in- and out-patients seeing the same specialist physiotherapist
- [illegible]

Improving respiratory physiotherapy services

CONTINUED

- Reduce length of stay in hospital and facilitate specialist physiotherapy respiratory care in local hospitals and the community
- Working with local hospitals who refer into our PICU to ensure optimal physiotherapy care for patients before retrieval to RHSC including online resources
- Improving out-patient care to patients with non-CF complex respiratory problems
- Provision of specialist respiratory community care to patients and skilling other community therapists in respiratory care
- Improved clinical communication with SEAT physiotherapists and beyond
- Working with National Centre for Scoliosis Surgery team to optimise pre- and post-operative planning for patients at risk from respiratory problems
- Network of specialist respiratory paediatric physiotherapists sharing education, evidence-based practice, SEAT clinical standards and guidelines
- Linking with WEST network to provide free education for all staff and Scottish national standards for care of patients with CF
- Taking part in the Scottish Muscle Network for patients with neuromuscular disease and providing expert respiratory care to physiotherapists including care pathway and joint working
- Providing online guidelines and educational resources via the Managed Knowledge Network
- Establishing physiotherapy referral and free access to all Local Authority Leisure facilities including education of gym staff
- Establishing provision of funded equipment locally and skilling physiotherapists to prevent patients having to travel to RHSC for tests, starting nebulised drugs or changing airway clearance techniques.

Outcomes of the investment will be audited including patient and family views but the hope is that all patients with complex respiratory illness in SEAT will see a specialist physiotherapist with the most up-to-date skills as close to home as possible.

> *"My daughter has complex neurological and respiratory problems. As well as her numerous outpatient appointments she has frequent prolonged admissions to RHSC with chest problems. The new respiratory community service has already been a godsend.*
>
> *Ava had a slight cough and Zoe was able to come out that day and also took a specimen. It turned out she was growing a nasty bug which she has had before and caused her to be quite unwell and have lots of admissions. This time a prescription was at my GP's for collection that day and Zoe arranged for her Respiratory Outpatient appointment to be brought forward.*
>
> *I am convinced that this has meant we have not had to wait until she was very unwell, the bug was harder to get rid of and she would have been in hospital again. Being in hospital is very difficult to manage with work, child care and family life. This service has brought expert care to my home and meant a much faster response than having to present to A & E."*
>
> Mother of a patient with complex neurological disability and chronic respiratory problems.

KETOGENIC DIET SERVICE FOR THE NORTH EAST OF SCOTLAND

HELEN GROSSI, KETOGENIC DIET COORDINATOR FOR THE NORTH AND OF EAST SCOTLAND AND
KATHLEEN ROSS, HEAD OF PAEDIATRIC DIETETICS, ROYAL ABERDEEN CHILDREN'S HOSPITAL, ABERDEEN

THANKS TO YEAR 2 NDP FUNDING, HELEN GROSSI HAS RECENTLY BEEN APPOINTED AS THE KETOGENIC DIET COORDINATOR FOR NESCANN, THE CHILD AND ADOLESCENT NEUROLOGY NETWORK FOR THE NORTH OF SCOTLAND.

The ketogenic diet is an evidence-based therapy for children with complex epilepsy. It is a treatment option that may be recommended by neurologists for children who have failed on two or more anti-epileptic medications.

This dietetic treatment is an individually calculated diet that is very high in fat, low in carbohydrate and adequate in protein. Normal diets contain about 40% of their calories from fat, ketogenic diets have twice that. The very low amount of carbohydrate in the diet forces the body to use fat in the form of ketones as an energy source. We don't know exactly how it works but high levels of ketones in the blood have an anticonvulsant effect. In effect the child is making their own drug from the fat in their diet.

Ketogenic diets were first used in the 1920s to treat intractable epilepsy, but with the introduction of a number of anticonvulsants over the years its use fell out of favour. However, in recent years interest has increased as a considerable number of children still do not respond to anticonvulsant medications.

There are 4 types of ketogenic diet in current use. These are:

2. The MCT Diet
3. The Modified Atkins Diet
4. The Low GI Diet

The most commonly used diet currently is the 4:1 Classical Diet. When using this diet, the dietician assesses the calorie allowance for each child and the protein levels are then set. From there the diet is calculated providing 80% of calories from fat and 20% of calories from carbohydrate and protein. Recipes are then calculated using this individual dietary prescription. Each item in the recipe must be weighed out using scales and it is important that all of the food is eaten. All children receiving ketogenic diet therapy require daily dietary supplements and have their bloods monitored 3-6 monthly to prevent any nutritional deficiencies.

KETOGENIC DIET SERVICE FOR THE NORTH EAST OF SCOTLAND CONTINUED

> "After a long wait, Cameron started on the ketogenic diet in January and we are seeing many positives. He is a brighter, happier and more alert child. He is beginning to notice the world around him, his concentration has improved and he is becoming more communicative. His small fluttery seizures have all but disappeared and the length of his generalised seizures has reduced considerably. Although it is still early days and there have been some teething problems, we feel that the chance of trying this diet is beneficial both to Cameron and our lives as a family."
>
> **Quote from Cameron's mum, a parent of a child recently started on the ketogenic diet.**

Commencing a child on the ketogenic diet requires an experienced dietician and significant commitment from the family. It is estimated that each family will require 20 hours of dietetic time for the first 3 months on the diet.

Due to the above time requirements, providing this service has been a challenge over the last few years. Only two or three dieticians in the North of Scotland were experienced in the treatment and they had no designated time to deliver a service. It was frustrating for consultants, dieticians and parents when children had to wait many months to start their diet. Improving access to a specialist therapy to the North of Scotland and Islands is exactly what the NDP aims to achieve.

Children who are successfully commenced on the ketogenic diet continue for approximately 2 years before they will be weaned off, while some children have been on the diet for considerably longer. Research has shown that approximately 38% will have seizure reduction and 7% have a greater than 90% seizure reduction. Anticonvulsants can be reduced in many children on the diet.

Helen will be working across Grampian, Highland and Tayside. As well as working with individual families, the top priority is to upskill local dieticians and increase awareness and understanding of the ketogenic diet amongst all professionals working with children with epilepsy. Helen is also working with colleagues in Glasgow, Edinburgh and throughout the UK to develop educational packages and other resources for families and professionals.

This new post will give significant opportunities for the development of the ketogenic diet in the North and East of Scotland, and the ketogenic diet is being researched as a possible treatment for other metabolic disorders.

Paediatric Cancer Services and Occupational Therapy – Developing a New Role

NATALIE LOW, SENIOR OCCUPATIONAL THERAPIST, ROAYAL HOSPITAL FOR SICK CHILDREN, EDINBURGH

"THE MOST EFFECTIVE WAY TO ENSURE THE VALUE OF THE FUTURE IS TO CONFRONT THE PRESENT COURAGEOUSLY AND CONSTRUCTIVELY."
ROLLO MAY, AMERICAN PSYCHOLOGIST

As we move well into the 21st century, we need to ensure that the service we provide to patients is constantly improving and developing. Patients deserve the best clinical outcomes and this is best achieved in an integrated service with improved access and quality of care.

The NICE guidelines, "Improving outcomes in children and young people with cancer", published in 2005, emphasise the need for Allied Health Professionals (AHPs) in the delivery of supportive care, rehabilitation and palliative care. It states that "building an AHP workforce that is skilled, competent, effective and efficient is pivotal to the long-term sustainability of specialist children's services".

My position as full-time Senior Occupational Therapist (Band 6), within Paediatric Oncology and Haematology at the Royal Hospital for Sick Children, Edinburgh, was created with National Delivery Plan (NDP) funding, following a detailed proposal highlighting the need for Occupational Therapy provision, within Paediatric Cancer Services, to meet current and future demands. I have been in post since March 2009 and this is a highlight of achievements to date.

ACQUIRING GREATER KNOWLEDGE AND SKILLS

I have been fortunate enough to have had numerous opportunities for acquiring knowledge and skills over the course of the year, which has further enhanced my clinical reasoning skills and quality of care provided. Benchmarking visits to other hospitals with an established OT service in paediatric cancer services, namely Great Ormond Street Hospital, University College Hospital, London, and Yorkhill Hospital, Glasgow were particularly enlightening and highlighted how large our role is within this area of specialty. Knowledge and skills acquired on courses and training days such as counselling skills, splinting and the NES funded programme "Advanced communication tutor training" have been pivotal to my learning. In the future, I hope to continue to assist and act as a resource for other team members so that key skills can be cascaded, improving service delivery in a number of areas of practice at RHSC and beyond.My designated role within Oncology and Haematology allows me time to be involved in the National OT Oncology Network which has recently published a COT (College of Occupational Therapy) paper "Guidance for Occupational Therapy with Children and Young People with Cancer". We are also currently looking into suitable assessments and quality measures for evaluation of therapy interventions.

Paediatric Cancer Services and Occupational Therapy – Developing a New Role CONTINUED

PROMOTING AND INTEGRATING THE OCCUPATIONAL THERAPY ROLE

Over the course of the year, I have continued to play an active part in promoting the OT role which has enabled me to become integrated into a large multi-disciplinary team. This has been achieved through attendance at all multi-disciplinary team meetings; carrying out teaching sessions with nurses, doctors, students and community support workers; inviting members of the MDT to observe therapy sessions and producing induction packs for new medical staff and students, to name but a few. Educating patients, carers and families has also been imperative. AHP information for Patient/Parent packs on Ward 2 has been prepared together with fellow AHPs. We are also hoping to roll out AHP information leaflets and videos (funding dependent) in the near future.

DELIVERING A HIGH QUALITY SERVICE

In line with NICE guidelines, this new OT post has enabled us to make headway in delivery of high quality care to children and young people with cancer, who otherwise might have had unmet needs with poorer clinical outcomes. As the OT in a Principal Treatment Centre, I continually co-ordinate care with other members of the team, both locally and in more remote locations, allowing a more seamless transfer of care which can only benefit our patients and their families. Multi-disciplinary team working is crucial within rehabilitation. My physiotherapy colleague (whose post was also established through NDP funding) and I have implemented a number of joint-working approaches such as joint assessments and treatment sessions (on the ward, at homes or in schools); an AHP referral form; joint documentation and planning future OT/Physiotherapy groups. We have also begun looking into a more integrated MDT continuing care pathway for children and young people on the ward and hope to present case studies at Grand Rounds in the near future. I have also set up therapeutic support groups for children undergoing chemotherapy/maintenance therapy and this project is funded by the Friends' Foundation. I hope to continue to run these groups, together with other team members at RHSC, as feedback from patients and parents, thus far, has been extremely positive. I represent all AHP therapy departments at the 'reprovision' meetings for the new RHSC to ensure that room space, layout and facilities available are conducive to the best quality of care that can be provided to children and young people. OT has an essential part to play in the Managed Clinical Network, CATSCAN (Children and Teenagers Scottish Cancer Network). The aim of CATSCAN is to improve standards in children and young people's cancer services by promoting evidence-based practice and ensuring that an equally high standard of care is available throughout Scotland. I am a member of the Executive Steering group, Survivorship and Rehabilitation group, Quality Measures group and act as chairperson for the Allied Health Professional subgroup. The AHP group has good representation from all disciplines from around Scotland and has driven forward a number of initiatives including "Definition of Roles and Criteria for Referral" to help raise awareness and ensure more timely referrals and a multi-professional "Rehabilitation Profile" to allow for more seamless transfers of care and better communication between health professionals on patients' recovery across health, community and education settings. We will shortly be forwarding this profile to other AHPs for use within their area of specialty. This AHP group has also been involved in education and training days and we hope to put together an education resource, together with NES, on core skills required for AHP staff working in cancer services.

Occupational Therapy aims to assist and enable a child to be "all that they can be". I hope this gives some flavour of how pivotal the role of the OT is within paediatric cancer services.

NEPHRO-UROLOGY - EXPANDING, SUSTAINING AND IMPROVING SERVICES VIA NDP FUNDS

DR D A HUGHES, CONSULTANT, HONORARY SENIOR CLINICAL LECTURER

FROM ITS ESTABLISHMENT AS A NATIONAL MANAGED CLINICAL NETWORK IN 2004, THE SCOTTISH PAEDIATRIC RENAL UROLOGY NETWORK, THROUGH THE WORK OF ITS STEERING GROUP, DEVELOPED A CLINICAL SERVICE MODEL TO SUPPORT DELIVERY OF SPECIALIST RENAL AND UROLOGY CARE LOCALLY, WHERE POSSIBLE, IN AN EFFECTIVE AND SUSTAINABLE MANNER.

A key factor in delivering effective care locally, in a sustainable manner, is the development of multi-disciplinary clinical expertise in the district general hospital units, supported by the specialist multi-disciplinary teams in the four children's hospitals. The NDP has funded consultant paediatric sessions, nurse specialist and paediatric dietician support in every DGH unit in Scotland. This resource will support renal and urology care of patients in local joint network clinics with visiting clinical specialists from regional centres. More importantly the local team will support continuing care of their patients with support from specialist colleagues in the regional children's hospitals.

The specialist clinical teams in the children's hospitals have received funding to increase the current renal and urology nurse specialist care in Aberdeen and Edinburgh and the establishment of renal and urology specialist nursing support in Dundee. Funding of renal and urology nurse specialists and renal nurse practitioner posts in Glasgow will support the delivery of dialysis care for in-patient and community-based care.

Additionally, the nurse specialist and practitioner support will enable the further development of nurse-led clinic services. Specialist renal dietetic support has been expanded in all four children's hospitals enabling support of local dieticians in DGHs, the development and implementation of nationally agreed treatment plans and more formal professional development. The complex nature of drug treatments and the impact of renal disease on drug management makes the additional support for paediatric renal pharmacist time in all four children's hospitals across the three regions most welcome. This will also assist the implementation of the award-winning patient-held Renal Medication Information Booklet used by patients with complex renal disease.

The provision of psychology support through increased funding directly to regional psychology services should allow children with complex renal and urology conditions to benefit from the development of local support from paediatric psychologists dealing with chronic illness in children.

In addition to funding of local Consultant Paediatrician time, additional funding of Consultant Nephrology time will support the implementation of joint renal clinics.

Maintaining clinical data for the routine care of patients with complex renal and urology conditions across Scotland and reporting to Scottish and UK renal and transplant registries would be unsustainable without secure resourcing of a database clerk. This funding, made secure by the NDP, will allow the national clinical network to build on an established renal database and work with future developments.

The co-ordinated pan-Scotland approach adopted by the NDP process has provided a unique opportunity to engage with regional health care planners in delivering specialised renal and urology services to local centres but with a national perspective. This forum provides a real opportunity to ensure equitable delivery of clinical services and the Scottish Paediatric Renal and Urology Network looks forward to working with clinical partners in implementing this new resource through Year 3 of NDP. It will also provide the benefits of locally delivered specialist care to patients and families.

CATSCAN
Children and Teenagers Scottish Cancer Network

IMPROVING CANCER CARE FOR CHILDREN AND TEENAGERS IN SCOTLAND

DR W. HAMISH WALLACE, MCN CLINICAL LEAD

THE OVERARCHING REMIT OF CATSCAN, WHICH WAS FORMED IN EARLY 2008, IS TO CO-ORDINATE A NEW MODEL OF CARE IN SCOTLAND BASED ON THE NICE GUIDANCE ON CHILDREN AND YOUNG PEOPLE WITH CANCER AND THE NDP. THIS HAS BEEN A MAJOR INFLUENCE ON THE CATSCAN AGENDA IN THE LAST YEAR. CATSCAN RECEIVED NDP FUNDING FOR THREE PROJECTS: THE ESTABLISHMENT OF A SENIOR MANAGER TO SCOPE THE DEVELOPMENT OF MULTI-DISCIPLINARY TEAM MEETINGS (MDTS); CREATION OF A TWO SESSION PALLIATIVE CARE CONSULTANT POST FOR CHILDREN'S CANCER (DR ROSALIE WILKIE) AND THE FUNDING OF A TWO-SESSION POST FOR CHILDREN'S CANCER (DR ANGELA EDGAR) TO SCOPE THE DEVELOPMENT OF A COMPREHENSIVE SYSTEM OF FOLLOW-UP FOR SURVIVORS OF CHILDHOOD/TEENAGE CANCER.

Below is an update of some significant recent achievements of CATSCAN:

The network has produced six two-minute information videos about common procedures in the treatment of childhood cancer. They can usefully supplement the written or oral information available to families with objective visual introductions to such things as going for a scan, having a central line inserted, or receiving chemotherapy. The videos will be launched on the CATSCAN website in the summer of 2010 by the Cabinet Secretary for Heath and Wellbeing (see http://www.catscan.scot.nhs.uk). This project is a first for both Scotland and the UK.

CATSCAN has developed and audited nationally agreed guidance on the use of blood products for children and young people with cancer. This will facilitate the safe and consistent management of patients treated nearer their homes at shared care centres for some parts of their care. A similar project on the management of febrile neutropenia is underway.

Clinical governance is an important role of CATSCAN. Careful analysis of the data from the Scottish Cancer Registry (SCR) and the UK National Register of Childhood Tumours (NRCT) has demonstrated that none of the Scottish centres has statistically significantly higher numbers of deaths than expected for any of the major tumour types. In fact the performance of all Scottish centres compares favourably with other centres in the UK on a number of different clinical indicators.

Improving palliative care for children with cancer is a clinical priority for CATSCAN. Much of the work of the palliative care group (Dr Dermot Murphy) and Palliative Care project post (Dr Rosalie Wilkie) has centred on the Living & Dying Well Action Plan. Two specific achievements are the implementation of the palliative care summary for C&YP with cancer and the development of a new form to help decision making for use with children and young people who are in the final (terminal) phase of their illness (Children/Young People Acute Deterioration Management (CYPADM) form).

Over 80% of children with cancer are alive five years after diagnosis and over 70% will become long-term survivors. A Late Effects Project Board has been formed under the leadership of Dr Angela Edgar. They have developed a template for the End of Treatment Summary and Care Plan (Health Passport), which will be provided to each patient/family at the end of treatment and a copy will be sent to their GP and other health professionals involved in the patient's care. Further work is ongoing to explore the feasibility of the options identified in earlier scoping work for the delivery of an electronic survivorship system.

Education and training remain important achievements of CATSCAN. The network hosted education seminars in June 2009 and December 2009. Topics that have been covered include: updates on ALL and brain tumour management, developments in palliative care, educational videos, changes in evolving management structures and the development of the MSN, supportive care and rehabilitation.

Finally, teenagers with cancer remain a lost tribe, requiring age-appropriate facilities and care which we hope to provide in Scotland in partnership with the Teenage Cancer Trust. Currently, efforts are underway to develop a UK specialist register of teenage and young adult cancers. The Teenagers and Transition Working Group is led by Dr Bob Grant and has been mapping existing services for teenagers and young people in Scotland.

The development of a Managed Service Network for children and young people with cancer is now settled government policy and it is the intention for CATSCAN to develop into the clinical governance and quality arm of the new MSN.

THE VALUE OF PSYCHOLOGICAL CARE: GRAMPIAN’S PERSPECTIVE

ANDY KEEN, CONSULTANT HEALTH PSYCHOLOGIST, NHS GRAMPIAN

CHILDREN WITH CANCER AND GASTROINTESTINAL CONDITIONS POTENTIALLY FACE A NUMBER OF SUBSTANTIAL PROBLEMS. OF COURSE, BEING DIAGNOSED WITH CANCER IS A FRIGHTENING EXPERIENCE FOR CHILDREN AND THEIR FAMILIES BUT THIS IS ONLY THE START OF WHAT CAN BE A CHALLENGING JOURNEY. MANY ASPECTS OF TREATMENTS CAN BE UNCOMFORTABLE AND CAN REQUIRE HOSPITALISATION FOR LONG PERIODS. TRYING TO REINTEGRATE INTO NORMAL LIFE AGAIN (GOING BACK TO SCHOOL, CLUBS AND MIXING WITH FRIENDS) DURING AND AFTER TREATMENTS CAN ALSO BE TOUGH. FOR MANY YOUNG PEOPLE AND FAMILIES LIFE WILL NEVER BE THE SAME AGAIN.

Gastrointestinal conditions such as ulcerative colitis can also impact significantly on children and their families. Many of the symptoms can be painful, debilitating and potentially socially embarrassing, which can lead to young people disengaging with life. Teenagers can be especially vulnerable to problems relating to their body image if they become cushingoid or require a stoma. Families have the additional problems that many gastrointestinal conditions are chronic and their course fairly random and to some extent out of their control. That’s exactly the type of problem that we all find difficult to deal with, even when things seem to be going well.

Needless to say, these stresses and strains can show in many different ways in young people and their families including anxiety, low mood, anger, frustration and aggression, difficult behaviour and conflict.

The Psychologist’s Role

As a direct consequence of NDP funding, we were extremely lucky to appoint Dr Olumurewa Akintola, clinical psychologist, to a full-time post in December last year. Half her time is allocated to oncology and half to gastrointestinal services. Ultimately, her aim is to improve emotional wellbeing commonly in the face of substantial adversity, and deal with other psychological and family issues that impede improved health and self-care. This means helping young people overcome difficulties already established and also trying to prevent problems from arising. This can only be achieved by working in many and varied ways. These have included:

- Face-to-face work with young people and families
- Meeting with young people soon after diagnosis
- Being integral to MDT discussions about young people and their management

- Being routinely present and accessible at medical clinics
- Co-working with colleagues such as specialist nurses and dieticians
- Providing liaison across health and education
- Conducting debriefs on those sad occasions when a young person has died

There is no doubt that much of the intense distress experienced by young people and their families is natural and normal. The job of a paediatric psychologist is to help young people and families manage this distress as best they can, using and developing the natural resourcefulness and resilience that is already present. Dr Akintola is laying important foundations because there can be no doubt that we are in the early stages of this process. There are exciting days ahead with impending plans to design and implement screening systems to detect significant emotional problems and associated care pathways, as well as a needs assessment of transition services. There is no doubt that having a psychologist as a member of medical teams, clinics and ward-based provision sends a very strong signal to young people and families that the hospital is interested in their physical and emotional wellbeing. Certainly, the psychology service that is now being delivered to young people with cancer and gastrointestinal conditions in Grampian has never been delivered before, and could not be delivered without the NDP funding.

KEY ACHIEVEMENTS from Year 2

WE ARE NOW OVER TWO YEARS IN TO IMPLEMENTING THE NATIONAL DELIVERY PLAN, AND WELL ON TARGET TO ACHIEVE THE COMMITMENTS MADE.

The delivery of local care continues to improve, with services expanding in order to offer specialist treatment at a local level. For example, in the North of Scotland 250 children with general surgery of childhood conditions were seen locally in 2009/10.

Patients are being offered more comprehensive treatment, such as dietetic and physiotherapy. Investment means this is now open to a greater number of patients than before.

The psychological aspect of care is becoming more embedded in service: there is now psychological input to oncology clinics, including those for long-term survivors, and in September a national stakeholder event will be held to present the draft educational resources developed by NES for all staff working in specialist children's services.

Transition for patients moving from paediatric to adult care continues to be a priority and is being addressed by individual networks, at local, regional and national levels. The RHSCE has established a teenage/transition clinic for rheumatology patients, with strong nursing and medical links to the young adult service at the Western General. A working group has been formed to consider transition at a national level and will propose how best to co-ordinate and address transition issues.

Networks are making valuable contributions to the improvement of care: the network for children with exceptional healthcare needs (CEN) has over 500 contacts spanning a broad range of agencies and has launched an education module for use by parents and staff. It has established four sub-groups to look at service users, data group, education and training, pathways of care and audit and research. It will hold a conference on 29 September on co-ordinating and improving services (see http://www.cen.scot.nhs.uk).

Regional MCNs have been established in the West for gastroenterology and respiratory medicine. Other networks are developing protocols, guidelines and pathways to bring consistency and improved patient experience. CATSCAN has developed six short videos aimed at patients and parents on dealing with different aspects of cancer, and the endocrinology MCN is planning to develop a comprehensive range of patient literature. A database for use by NMCNs is being developed which will allow clinicians to access patients' records remotely and compare performance in their specialty across the country.

KEY ACHIEVEMENTS

CONTINUED

The adolescent care education resource, commissioned by NES, is currently out to consultation and will be delivered by March 2011. Work is ongoing to align medical education with specialist services requirements, and a clinical fellow has been appointed for three years to design educational materials for the ST4+ training programme.

Telehealth plays an important part in delivering education, and continues to support clinical education programmes in Edinburgh, Glasgow, Dundee and RCPCH. The value of telemedicine in other areas is also being exploited: babycam systems have been installed in Ninewells and the Southern General and discussions are ongoing with child protection clinicians to explore the suitability of using video equipment to support forensic examinations. The national roll-out of telemedicine equipment is on schedule for completion in 2010/11 – over 22 systems have been installed to date and a further six upgraded.

The paediatric patient safety programme is gathering pace and has been received very warmly so far, with over 120 delegates from a range of disciplines attending the launch event in June. Nine Boards have identified a paediatric patient safety lead, with the others expected to follow suit shortly. The programme has set itself the ambitious goal of a 30% reduction in adverse events by June 2013 and has developed a paediatric trigger tool to help achieve this. For further information on this programme please contact Julie Adams (julie.adams5@nhs.net).

Through innovative planning and collaborative working, staff working in specialist services are improving their skills through taking on expanded roles, e.g. physiotherapists leading joint injection sessions, peer training and joint management of complex patients. Careful workforce planning and investment in administrative support is also allowing specialist staff to take on additional roles they could not previously have done, such as attending ward rounds and leading network sub-groups.

As you can see, a vast amount of work has taken place as a result of the NDP. But what impact is all this having upon the patients themselves? Clinicians and planners report the following notable improvements:

- Dedicated paediatric staff where previously patients may have had to rely upon the adult service having capacity to deal with referrals
- Improved transition to adult services
- Reduced referral times and length of hospital stays
- Reduced hospital admissions and outpatient appointments
- Stronger link between acute and community services
- Continuity of care between hospital and home environments
- More effective use of available resources – non-clinical tasks now being carried out by admin rather than clinical staff
- Shared care management of complex patients across specialties – more patient-centred approach.

This is a very encouraging picture. We look forward to seeing how the additional investment in Year 3 builds upon this to improve the quality, access and sustainability of all specialist services.

For a fuller version of Year 2 achievements please see the website:
www.specialchildrensservices.scot.nhs.uk

The Scottish
Government

APS Group Scotland
DPPAS10094 (08/10)

www.specialchildrensservices.scot.nhs.uk/