

BSDH



UNLOCKING BARRIERS TO CARE

**Developing Care Pathways for People
with Down Syndrome
Friday, 13th May 2005**

Bristol Marriott Royal Hotel, College Green, Bristol

Abstracts

Focusing on the Early Years - first steps on the pathway

**Dr Paula Sneath MB, BS, FRCP, FRCPCH, DCH - Consultant Paediatrician,
Epsom General Hospital**

Dr Sneath has worked at Epsom General Hospital for the past 20 years. During that time, she has been the Paediatrician caring for the majority of the children in the locality who have Down's Syndrome.

Dr Sneath has been involved in many other initiatives e.g. setting up JOG - Junior Opportunity Group, where mothers with babies and toddlers who have special needs are able to meet once a week and have access to a number of health professionals at the same site.

Aim

To give an overview of the professional input from before birth to adulthood offered to people with Down's Syndrome

Outcome

An understanding of the multi-agency professional input available for people with Down's Syndrome

Abstract

This talk will draw upon both personal experience and national guidance in areas of health, education and social support

How to develop an Integrated Care Pathway

Paul Batchelor - Senior Lecturer and Honorary Consultant, the London Hospital

Course Director Certificate in Dental Leadership and Management and Research Director, FGDP and Honorary Senior Lecturer in Dental Public Health UCL. Paul qualified from Liverpool in 1980 and worked in the Community Dental Service, the Hospital Dental Service and in General Dental Service. While as a practitioner he gained his MSc from the Birmingham University and subsequently moved to London as a lecturer at the Royal London Hospital where he completed his PhD. He then moved to Kings College London to take the position of Senior Research Fellow and in March 2000, to University College London as Senior Lecturer and Consultant in Dental Public Health. In 2001 he was awarded a Fellowship by the FGDP where he currently holds the post of Research Director and Course Director.

Aims

- To explore the current situation regarding care pathways and dentistry
- To review the implications for people with Down Syndrome

Outcomes

- To outline the basis for the introduction of care pathways
- To increase knowledge and understanding of how care pathways are developed

Abstract

The presentation will outline the basis for the introduction of care pathways and explore the current situation in dentistry and the possible implications for people with Down's Syndrome.

The Transition to Adulthood

Dr Glyn Jones - MBBCh MSc MRCPG MRCPsych Consultant Psychiatrist, Bro Morgannwg NHS Trust, Cardiff

Dr Glyn Jones trained in his native South Wales, initially in General Practice and subsequently in Psychiatry. He has been a Consultant Psychiatrist in Learning Disability in Cardiff for the last 7 years.

He has a special interest in the health care needs of people with Learning Disability and is an invited member of the Royal College of Psychiatrists Special Interest Group on Learning Disability and the Royal College of Psychiatrists Scoping Group on the physical health of people with Mental Health problems.

He is a co-author of a series of research projects relating to the physical health of people with Learning Disability in association with colleagues from the Welsh Centre for Learning Disability and has lectured on this subject at a variety of local and national meetings.

Aim

- To explore potential barriers to a seamless transition to adulthood

Outcome

- To provide possible solutions to overcoming these barriers

Abstract

The transition to adulthood is daunting for even those with optimum health and social circumstances. For those with potential deficits in physical and adaptive functioning there are considerable barriers. Despite increasing awareness of these problems the aspiration of a seamless transition is rarely fulfilled. The presentation will explore barriers and possible solutions.

My Dental and Health Care Experiences

Miss Caroline Jolly

Caroline is 26 years old and has Down Syndrome. She was fostered and then adopted by her mother, Mrs Anne Jolly.

Following her education at school, Caroline went on to study Vocational Catering and Retail plus Access to Employment at East Surrey College. She has attained her Level 1 NVQ in Catering.

Caroline worked for 4 years on a voluntary basis as a Catering Assistant in a Café and then followed this with 4 years full time employment. Sadly, she was made redundant recently when the Café closed down.

She is currently working voluntarily for her sister in an office, using her computer skills.

Caroline loves drama and belongs to a group called 'Acts'. She has performed in their 'Blood Brothers' production and also, in various other local shows.

Caroline also likes reading books on crime/thrillers and has recently finished a large book on 'Jack the Ripper'. Her other main interest is music, particularly Gareth Gates, Bon Jovi and Meatloaf.

Aim

- To describe the health experience from a patient's perspective

Outcome

- To understand what we can do to improve the patient's journey through the Health Care System

Abstract

The presentation will take the format of an interview with Selina. Together they will focus on some of the health issues that Caroline has had to cope with over the years, from birth through to the current time.

A Mother's Perspective

Mrs Donna Self

Donna has a background of working in healthcare; a total of 9 years within Adult Rehabilitation and the past 16 months, for the Speech and Language Therapy Team at East Elmbridge and Mid Surrey PCT (EEMS).

She is also a busy mother of Natasha (budding dance champion) and Andrew, who has Down Syndrome.

Andrew has been under the care of Dr Sneath since he was 2 weeks old and had an early referral to the 'Special Smiles' dental service in EEMS

Aim

- To create an awareness of the Health Care experiences one family faced

Outcome

- To increase knowledge of appropriate ways in which Health Care Professionals should approach parents
- To highlight the fact that the parents will have faced many difficult times already and that any new HCP's should be sensitive to the emotional state of the parents. New information is not always readily absorbed and should be written down

Abstract

Donna will enlighten the audience regarding the health care experience from a parent's point of view. She will focus on the various medical and surgical interventions which Andrew has had in the past. Donna will also mention some of the unusual quotes/comments that parents often have to cope with from a range of services.

Oral Function in persons with Down Syndrome - aetiology and prevalence

Dr Denise Faulks BDS MSc Hospital Practitioner in Special Care Dentistry, University Hospital of Clermont-Ferrand, France.

Denise Faulks completed her dental degree at the United Dental and Medical Schools of Guy's and St. Thomas' Hospitals. She worked at Guy's Hospital and then at Aberdeen Royal Infirmary before moving to France in 1997 to join Prof. Martine Hennequin of the Special Care Unit at the University Hospital of Clermont Ferrand. She holds an MSc in Dental Public health from the University of London. She works full time at the special care unit which manages the dental needs of children and adults with physical, mental, medical and social disabilities. She is also involved in teaching Special Care Dentistry to undergraduates and conscious sedation to postgraduate students. Research interests include:

- i) The study of the orofacial problems associated with Down Syndrome, including epidemiology, treatment and functional and social impact
- ii) Conscious sedation for the population with intellectual disability
- iii) Definitions of the population requiring special care within the biopsychosocial model.

Aim

- To describe the structural and functional characteristics of this group of patients

Outcome

- To increase awareness of the impact that orofacial dysfunction has on their daily life

Abstract

Persons with Down Syndrome are subject to characteristic orofacial development and dysfunction.

A study into the prevalence of problems will be presented and the difficulty of access to appropriate treatment evoked.

Further down the road - older age issues and Down Syndrome

Dr Janice Fiske BDS (London), FDS RCS Eng, Mphil (London University), Diploma in Dental Acupuncture (BDAS)

Janice Fiske is currently Divisional Director for Ambulatory Patient Care GSTT NHS Foundation Trust; Senior Lecturer/Consultant in Special Care Dentistry in the Department of Sedation and Special Care Dentistry at GKT Dental Institute of King's College London; and Honorary Senior Scientific Adviser to the Chief Dental Officer for England.

She qualified from the London Hospital Dental School in 1973. Since then she has worked in the Community and Hospital Dental Services providing oral health care for people with disabilities, mental illness and complex medical conditions; delivering undergraduate and postgraduate teaching; and carrying out research related to Special Care Dentistry.

Her research interests include the use of acupuncture in dentistry; the emotional effects of tooth loss; the use of air abrasion and Carisolv gel as a non-invasive technique for caries removal in anxious patients; and the use of chlorhexidine and fluoride varnishes to prevent root caries in a residential elderly population. She was President of the British Society for Disability and Oral Health in 1990 and President of the British Society of Gerodontology in 1997 and remains active in both Societies. She is currently Chairperson of the Joint Advisory Committee in Special Care Dentistry, an elected member of the Dental Faculty Board of the Royal College of Surgeons of England, a member of the Health Council of the Prince of Wales Disability Partnership and Adviser on Oral Health to the Down's Syndrome Association for England.

Aim

- To reinforce the message that, despite what the dental literature might lead one to believe, Down's Syndrome is not just for childhood it is for life

Outcome

- To have provided some awareness of the oral health challenges for adults with Down's Syndrome

Abstract

This talk will have 3 strands:

1. Its main focus will be on an investigation into the experiences and expectations of relatives of adults with Down's Syndrome (DS) regarding oral health care, and factors impacting on access and experience of dental care for this group. This research comprised a two phase qualitative and quantitative study utilising in-depth interviews with a convenience sample of 6 relatives, and a postal questionnaire survey of 200 parents/carers, respectively. It was undertaken by Paul Kaye as part of the requirements for his MSc in Sedation and Special Care Dentistry, and supervised by me. The main themes elicited from the qualitative interviews related to concern, experiences, parents/carers' attitudes, preferences and information. Additionally, a number of sub-themes were identified. This information was used alongside the dental literature and the researchers' experience to design a questionnaire to gather quantitative data. The response rate from the postal questionnaire was 63.5%. It informed us that although adults with DS attended the dentist regularly, on the whole, they received little restorative treatment. Additionally, their experience of oral health care was influenced by the attitudes and skills of dental health professionals, stigmas and relatives' expectations of dentists, their oral health beliefs, information and support received, and knowledge and priorities. Relatives were clear about the professional qualities they expect in dentists and would like them to be proactive in providing more information on oral health issues in collaboration with other health and social care professionals.
2. The talk will also draw on some of the situations relating to oral health and dental treatment that I have been asked to advise on by the Down's Syndrome Association (for England).
3. Finally, it will focus briefly on the challenge of tooth replacement for the adult with Down's Syndrome.