

# Improving Patient Access to Education Resources: The Development of an Educational DVD for Congenital Adrenal Hyperplasia (CAH)

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## Introduction

**Patient education** is an essential part of health care management, and the primary responsibility of all health care professionals. Any initial education process varies dependent on the timing from the diagnosis.

- Health care professionals (HCP) need to be sensitive to the impact the diagnosis has on the coping skills and adaptive processes of the family. Consideration of literacy skills and comprehension, will assist in the appropriate timing of information delivery, and should focus on essential information initially, followed by a more structured process at an appropriate time.
- Health Education is critical to the needs of families with chronic illness. Knowledge and understanding (literacy and comprehension) of what is being taught is critical to achieving positive outcomes for the child and family, both from a physical and psychosocial perspective.
- Understanding what influences learning is essential: family system and response to illness, coping strategies and cultural influences. Strategies need to optimise health outcomes: child, family and community.

## Background

**Congenital Adrenal Hyperplasia (CAH)** is a rare inherited condition with a 1:4 recessive inheritance. An incidence of 1:15,000 with a carrier status of 1:50. In Asian populations incidence appears higher.

An *enzyme defect* leads to glucocorticoid and mineralocorticoid deficiency, leading to salt losing adrenal crisis, shock and death; plus

- *Androgen excess causes*:- ambiguous genitalia, early puberty, short stature and infertility.

### Psychosocial Issues:

- Parental vulnerability: overwhelmed by diagnosis, medical interventions and terminology.
- Burden of responsibility: of level of care required, threat of illness and injury, life long management, gender determination: counselling and disclosure.
- A state of "cognitive paralysis" is described: from the shock, grief, fear and confusion that occurs following diagnosis, impairs knowledge attainment.

### Management:

Management of CAH is life long, and requires good and understanding of the disorder, and the action required to manage clinical problems that arise. Expertise is usually limited to specialist centres.

**Effective education initiatives are essential** and of vital importance in helping families to manage the condition and maintain compliance.

## Aim

- To improve patient access to educational resources, and patient outcomes through increased knowledge and understanding.
- Extend the comprehensive Psychosocial Education Program( PEP) developed for families with CAH, to the wider population of patients with the condition, both in Australia and in South East Asia.
- Achieve these aims by developing an educational resource in DVD format accessible to all families with a child with CAH.

## Method

### Why a DVD for health education?

Multimedia health education addresses all learning needs: auditory, visual and psychomotor domains: participant can watch, listen, read and revise information. Target audience is the primary consideration in deciding on detail and comprehension of content.

### How we did it?

Family and HCP consultation informed the PEP, which was implemented and evaluated and transposed into a DVD format:-

- speaker presentations filmed and recorded
- scripts transcribed verbatim,
- speaker slides graphically designed, edited and formatted in line with each speaker presentation.

**The DVD titled: "The CAH Family Workshop"** is a structured comprehensive psychosocial education program that can be facilitated by one health professional. Quotation and funding was sourced for development and translation.

### Program Goals and Objectives

Addressed educational and psychosocial issues to.

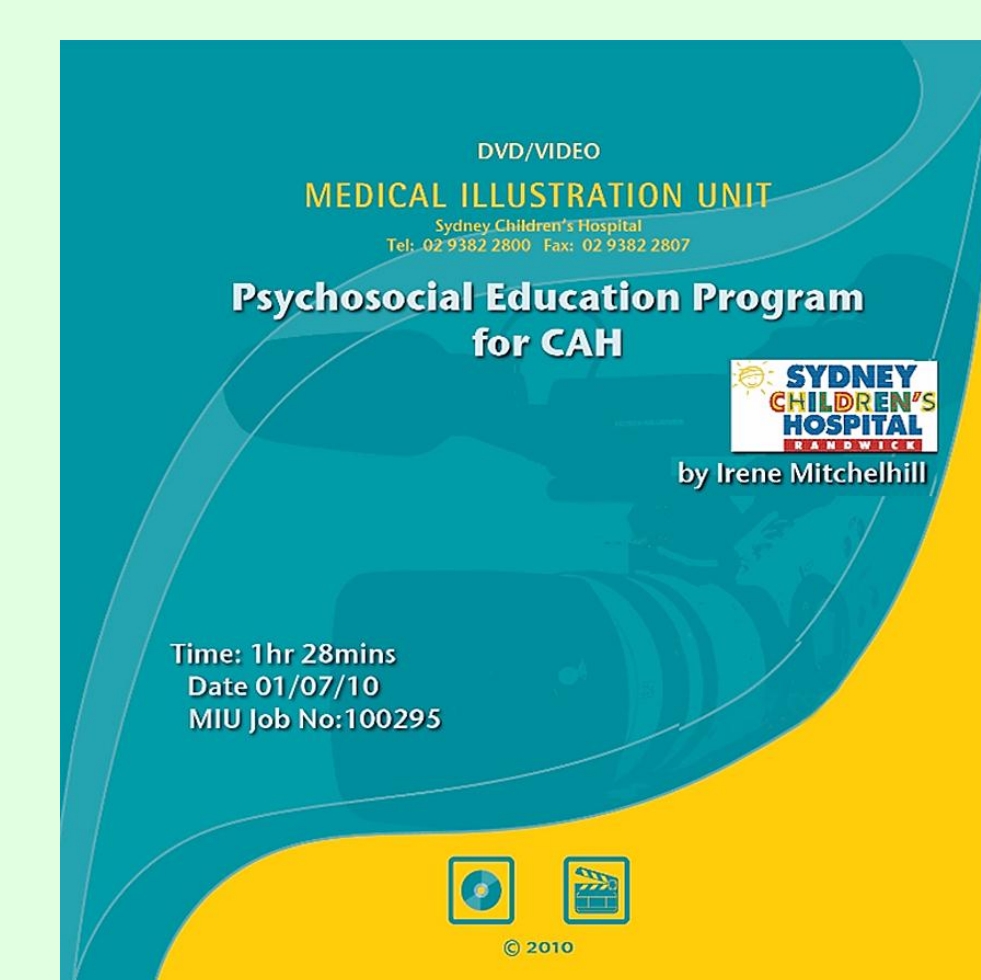
- Teach facts and skills
- Discuss the complexity of psychosocial concerns experienced with CAH.
- Provide practical skill enhancement and resources

### Evaluation

Maximum knowledge and satisfaction achieved. Pre and post test measures<sup>1</sup>.

## Program chapters

- Chapter 1: What is Congenital Adrenal Hyperplasia, diagnosis & management**  
Presented by Dr Charles Verge Paediatric Endocrinologist, Sydney Children's Hospital.
- Chapter 2: Adolescent and Adult Issues.**  
Presented by Professor Kate Steinbeck Consultant Adolescent and Adult Endocrinologist Sydney Children's Hospital.
- Chapter 3: Psychological Issues.**  
Presented by Ms Julie Kozyk, Consultant Clinical Psychologist, Sydney Children's Hospital.
- Chapter 4: Sick Day Care.**  
Presented by Ms Irene Mitchelhill, Clinical Nurse Consultant Sydney Children's Hospital.
- Chapter 5: Emergency Injection of Hydrocortisone.**  
Presented by Ms Irene Mitchelhill, Clinical Nurse Consultant, Sydney Children's Hospital.



## Conclusion

While knowledge is an important component of education programs, their effectiveness is contingent upon **teaching strategies and structure of information**<sup>3</sup>. HCP's must understand factors that enhance or inhibit knowledge attainment. There must be a readiness to learn and relevance of information<sup>2</sup>.

**A structured approach** to health education has long been acknowledged to be more effective in improving patient knowledge about their health condition, than relying on the "ad hoc" information received whilst in hospital or at clinic visits<sup>4</sup>.

The move to **multimedia learning methods**, which are patient specific, structured and culturally appropriate are appealing to those with literacy or language difficulties, but also to all learners. Audio, video, CD and DVD formats which include descriptive diagrams, illustrations and demonstrations appeal to all learning situations, and in combination written information provide a comprehensive approach. Because of its validated content and evaluated effect, this is far more appropriate than the "information highway" often sourced on the internet.

## References

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## Acknowledgements:

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## Psychosocial Education Program for CAH - DVD

Welcome to the CAH Family Workshop, an education program developed for families with Congenital Adrenal Hyperplasia  
The total program takes approximately 1.5 hours to play

- You may choose to view any one of the 5 chapters individually by clicking on the chapter number from the main menu
- If you have any questions about the information presented in this program, please discuss this with your health professional