



**Medical Management of Children  
And Young People with Down syndrome**



**Training Module  
First Edition- 2015**

Department of Women and Child Health  
Directorate General of Primary Health Care  
Ministry of Health  
Sultanate of Oman

(ML-108)

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## Preface

Down syndrome is one of the most common chromosomal abnormalities in Oman, the birth prevalence is estimated to be 2.4/1000 LB. This translates to about 120 births per year. Individuals born with Down syndrome are at risk for a number of associated medical conditions such as congenital heart disease, impaired hearing, gastrointestinal tract anomalies, thyroid disorders, and cataract among others. Health care providers need to be aware of these conditions as some warrant immediate intervention and medical attention.

In view of the increasing numbers of children with Down syndrome and the need to provide them with systemized medical care, it was endorsed in the 8<sup>th</sup> five year cycle of planning to develop a care pathway for children born with Down syndrome.

In view of the above, Department of Women and Child Health has developed a Local clinical guidelines based on the latest evidence available from the Down Syndrome Medical Interest Group, UK and Ireland (DSMIG) and evidence from the American Academy of Pediatrics (AAP). These guidelines were reviewed by UNICEF, assisted by experts from DSMIG in consultation with Down Syndrome International (DSi).

Following guideline development there is a need to build capacity of local health care providers for management of children with Down syndrome and for counseling of their families. A national TOT workshop was done on October 2014 where 7 master trainers certified. Consequently, a training manual is developed based on the national guideline aiming towards the in-service training of health care providers who are involved in providing health care to those children. This training manual is a valuable tool to unify the training process all over the Sultanate and assure that all needed information is delivered within the same setting.

With immense gratitude we wish to thank all those individuals who have contributed to the development of this module.

Dr. Fatma Ibrahim Al Hinai  
Director, Dep. Women and Child Health

## Module Overview

This training module consists of 16 sessions covering issues related Down Syndrom; definition of Down syndrome, System Review of Health-Related Aspects of Down Syndrome and planning an age- related surveillance system.

It also includes group work discussions covering different issues for example; current believes, given the news and principle of good practice. The participants will present a small presentation at end of each group work discussion.

This training module is designed to be run by master trainers in the governorates for a three days' workshop.

An electronic copy of the module (CD) will be provided with this hard copy to facilitate the smooth running the workshop in the governorates. The CD contains all power point presentations and materials needed on training.

## **Acknowledgment**

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- Dr. Moza Nasser Al Hatmi, Head of Child Health Section, Department of Women and Child Health.

We also acknowledge peer review and comments on this manual by Ms Juanita Singh Roshmi, Public Health Specialist, office of DGPHC. Support of the DSi Team and UNICEF is also highly appreciated.

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# DAY (1)

## Day (1) Program

<b>Time</b>	<b>Subject</b>
07:30-08:00	Registration
08:00-08:30	Session 1 - Training Module Introduction
08:30-09:30	Session 2 - What is Down syndrome? Practical overview lecture style of the genetics of Down syndrome
09:30-10:00	Session 3 - Explore current beliefs
10:00-10:20	Session 4 - Giving the news
10:20-10:50	Break
10:50-11:30	Interactive role play
11:30-12:15	Session 5 - Principles of Good Practice
12:15-12:30	Session 6 - Concept of guideline
12:30-14:30	Session 7 - System review of health-related aspects of Down syndrome
14:30-15:30	Lunch break

# **Session 1**

## **Module Introduction**

## Session 1: Module Introduction

### Session Outline

#### Mini lecture

<b>Activities</b>	<b>Time</b>	<b>Material and Resources</b>
<a href="#">Activity 1.1</a> Mini lecture About the workshop Aim and objectives of the workshop	15 min	Power point slide
<a href="#">Activity 1.2</a> Mini lecture Why Down Syndrome?	10 min	Power point slide

## Session 1: Module introduction

Time: 30 Minutes

### *Activity 1.1 (15min)*

*Welcome introduction:*

- Welcome to Participants to the National TOT Training Workshop on Down Syndrome Management.
- Explain that this workshop is a TOT Training and provide information on Down syndrome Management.

*Learning Objectives:*

Display the objectives on the slide and go through them:

1. To be able to understand and summarize modern genetic concepts and how they relate to Down syndrome.
2. To evaluate social constructs in Oman and how they might influence healthcare delivery for people with Down syndrome of all ages.
3. To define the essential criteria for healthcare screening programs and apply those principles to what we know of medical aspects of Down syndrome.
4. To define medical aspects of Down syndrome which do not lend themselves to screening.

### *Activity 1.2 (10min)*

Lecture

Explain why should discuss Down syndrome?

Some statistical data of Sultanate of Oman.

## **Session 2**

# **What is Down syndrome?**

## Session 2: What is Down syndrome?

### Session Outline

<b>Activities</b>	<b>Time</b>	<b>Material and Resources</b>
Activity 2.1 Introduction Discussion	15mins	
Activity 2.2 Lecture: “Genotype to phenotype opportunity”.	45mins	*The handout for power point presentation.

## Session 2: What is Down syndrome?

### *Activity 2.1 (15min)*

- *Introduction Discussion:* Interactive discussion to ensure all participants identify their work role, locality, type of practice and reasons for attending the course.

### *Activity 2.2 (45min)*

The master trainer will go through the lecture ‘*Genotype to phenotype opportunity*’. These notes act as guidance for presenters on how best to use the provided illustrative material. Different teachers will of course use different styles to encourage course attenders to understand the main learning points. These notes will help clarify the key learning points from each set of slides.

### **Doctors and Down syndrome – 2014 perspectives Genotype to phenotype to opportunity**

This lecture presents key facts about:

- The underlying biology of Down syndrome
- The consequences for development of neural circuits
- What this underdevelopment means for learning
- Standards for studying intervention studies and how there is no robust evidence of a positive effect for intervention to date
- Antenatal diagnosis
- The International Classification of Functioning, Disability and Health – Children and Youth version and what it should mean for service organisation
- How doctors might work closely with other agencies to encourage the participation of young people with Down syndrome.

Each Slide should take a minute to present – with some minor variations. It is suggested that the lecturer is well rehearsed in the educational content of this lecture and consult the Mac Keith textbook on any issues which are unclear, otherwise this timing will be difficult to meet.

There are 40 Slides

**Slides 1-13** address modern concepts of epigenetics. The lecturer should have knowledge and understanding of the key issues. The concept that one gene produces one protein and therefore the features of Down syndrome are the result of an over-expression of genes (gene dosage effect) no longer holds true.

The resulting genetic mechanisms are clearly complex. It seems very unlikely that a simple measure such as vitamin administration could improve outcomes but a number of writers and some studies have suggested this.

**Slide 13** presents the minimum standard for study design that might show such benefit. It emphasises that but for one no studies to date have met these requirements.

**Slides 14-16** summarise published studies. For guidance Chapter 19 in the Mac Keith text addresses these issues.

**Slide 17** points out the same lack of effectiveness for Interventions Involving Manipulation or an Invasive Procedure.

**Slide 18** emphasises a consistent predictor of educational performance is maternal secondary educational attainment.

**Slide 19-20** summarises the Manchester Down syndrome cohort study and emphasises good design and multi-variant analysis. Again full details are in Mac Keith Chapter 19.

**Slide 21** summarises possibilities for ante-natal screening including the good potential of cell-free fetal DNA testing (see Chapter 3 of Mac Keith book).

**Slide 22** emphasises the population effect of an increase in mean maternal age in Western Europe, how pre-natal diagnosis has increased the number of terminations keeping numbers born with Down syndrome static and how more widespread screening with newer techniques has increased the proportion diagnosed in mothers under 35 years of age.

**Slides 23-24** summarise the net effect on nerve cell development and of course intellectual disability.

**Slides 25-27** present the range of ability in Down syndrome and intellectual strengths and weaknesses.

**Slides 28-30** present the important features of modern terminology, within the structure of the WHO document International Classification of Functioning, Disability and Health – Children and Youth version. The lecturer should be acquainted with this important document and the important issues of social context and participation which should be written into all therapy care plans.

**Slide 31** summarises how inclusion and participation might be achieved for all disabled young people if doctors therapists teachers and society at large work together to create opportunity and encouragement (which is what every child on earth needs).

**Slides 32-33 address** individual and societal attitudes that need to be addressed before the environment can be changed and adapted to the advantage of disabled people.

**Slide 34** indicates how one young man with Down syndrome is not disadvantaged in all settings if given the opportunity. The disadvantage of a disability is situation-specific.

**Slide 35** is a slide addressed to an English-speaking audience but I am sure it can be adapted for Arabic-speakers. It talks of words to use for disabled people and words to use because they are prejudicial, rude or derogatory (I am sure every language has them!).

**Slide 36** – emphasises this point by stating all disabled people are people first with a name!

**Slides 37-39** make the point that Down syndrome is not an illness but may be associated with health issues which require surveillance of even screening. We shall be addressing these issues in the rest of the course. Maintaining health is part of offering opportunity and encouragement.

**Slide 40** encourages the audience to reflect on the circumstances in which they work, what might be achieved for young disabled people including those with Down syndrome, what barriers prevent progress and how working together might help those barriers be overcome.

# **Session 3**

## **Explore current beliefs**

### Session 3: Explore current beliefs

#### Session Outline

<b>Activities</b>	<b>Time</b>	<b>Material and Resources</b>
Activity 1.1 Discussion	30mins	flip chart

## Session 3: Explore current beliefs

Time: 30 minutes

### *Activity 3.1:*

#### *Group Discussion:*

The purpose of this activity is to look at attitudes to a child with Down syndrome and the care of the child. Participants are encouraged to express their thoughts on what it would be like to be a parent of a child with Down Syndrome. To consider what it feels like for that child at school, what the parents expectations are, what society's expectations and attitudes might be in Oman.

- How would you feel as a parent of a child with Down Syndrome?
- What would your expectations for your child be?
- Would you feel optimistic or pessimistic?
- Would you be well accepted and supported in your community?
- If I were that young person with Down Syndrome what would my life at school and outside school be like?
- Could I get a job?
- Could I live on my own?

Participants are asked to explore these issues in conversation with a partner in the group and then report back their thoughts.

# **Session 4**

## **Giving the news**

## Session 4: Giving the News

### Session outline

<b>Activities</b>	<b>Time</b>	<b>Material and Resources</b>
<p><a href="#">Activity 4.1</a> Practice Giving the news to parents Role play</p> <p>Reflective discussion with partner and with the whole group about how the 'parent' or the 'news giver' felt</p>	10mins.	Interactive work in pairs one is parent one is professional breaking the news
<p><a href="#">Activity 4.2</a> Giving the news to parents watched by whole Assembly. Role play</p>	10mins	2 groups of 4 role play This can be videoed if desired to review

## Session 4: Giving the News

Time: 1 hour

### *Activity 4.1:*

#### *Role play*

- Role -play of giving the news to parents that their child has Down syndrome. What does it feel like for parents? Expectation/loss.
- Ask two volunteers to play role play; one as a parent and one as doctor who break the news to the parent that his/her baby has Down syndrome.
- Ask the rest of the group to observe and comments later after the finish of the role play. Discuss with the whole group the positive and negative points. Remember the importance of body language.
- Repeat the role play with new participants

#### Important points to cover by the participants when breaking the news:

- Reference should be made to the **Scope Guidelines** in relation to this section.
  1. News should be given as soon as possible and in a positive way.
  2. Both parents if possible should be present, with the baby, and the interview should be in a comfortable setting.

It is helpful to recognize with the parents the various features which lead you to make the diagnosis. It can be helpful to hold the baby while doing this.
  3. The doctor must allocate enough time to appear relaxed and not rush the consultation.
  4. The person giving the diagnosis should be well informed and prepared to acknowledge what they do not know.
  5. They should reflect back to the parent what they have said, and check the parents' understanding.
  6. The parents should be offered an appointment to meet the 'news giver' again at an early opportunity to ask further questions.

### *Activity 4.2:*

#### *Role play*

- Ask for volunteers to form two groups of four people; a doctor, supporting nurse and two parents.
- To play the role play using case scenarios in annex (1) and the rest of the group to observe and record their comments for later discussion of strong and weak points of the doctor and nurses on their way of breaking the new.

# **Annex 1**

## **Session 4: Giving the news**

### **Activity 4.1**

### **Activity 4.2**

**(Case scenario)**

### *Activity 4.1:*

#### *Case scenario:*

This is the couple's first baby. They do not know anything about Down Syndrome. The baby is floppy and has features of Down Syndrome, but does not appear to have any health complications, has a normal heart and no G-I problems. The mother feels there is something wrong because the baby is so floppy, but the father thinks everything is fine

### *Activity 4.2:*

#### *Case scenario.*

This baby was born 2 weeks ago in a rural area. No-one has said anything to the parents about Down Syndrome, but this is the couple's third baby and they know he is not right. He is not feeding well and he has poor tone. They want to know what is wrong!

This scenario should demonstrate the added difficulties in giving a delayed diagnosis to parents, although this is common practice in Oman.

**Session 5**  
**Principle of Good Practice**

## Session 5: Principle of Good Practice

### Session outline

<b>Activities</b>	<b>Time</b>	<b>Material and Resources</b>
Activity 5.1	40min	Group Discussion

## Session 5: Principles of Good Practice

Time: 40 minutes

### *Activity 5.1*

- Divide the participants into six groups.
- Discuss the principles of good practice.
- Ask one presenter from each group to present (5 minutes each).

The group should discuss their observations from the role play and decide what makes the interview good and what was poor in relation to sharing information with the parent. They should agree an optimal way to conduct such an interview and present the key requirements to the rest of the course participants.

Examples of good practice would be:

- A thoughtful caring approach
- Acknowledging what you knew or did not know.
- Checking back with the parents that they were understanding what was being said.

(All of the principles will be found in the Scope Guidelines)

# **Session 6**

## **Concept of the Guideline**

## Session 6: Concept of Guideline

### Session Outline

<b>Activities</b>	<b>Time</b>	<b>Material and Resources</b>
<p data-bbox="203 642 381 678"><b>Activity 6.1</b></p> <p data-bbox="203 688 321 724">Lecture</p> <ul data-bbox="251 741 894 1178" style="list-style-type: none"><li data-bbox="251 741 894 829">• Why Specifically Consider the Needs of Children with Down Syndrome?</li><li data-bbox="251 842 654 877">• Methodology to Follow</li><li data-bbox="251 890 586 926">• Levels of Evidence</li><li data-bbox="251 938 735 974">• Oman developing Guidelines</li><li data-bbox="251 987 894 1075">• Essential criteria for healthcare screening programs</li><li data-bbox="251 1087 865 1178">• A summary of SIGN/NICE procedure for evidence.</li></ul>	15 min	Power point presentation

## Session 6: Concept of the Guideline

**Slide 1** covers why guidelines are necessary for children with Down syndrome

**Slides 2, 3 & 4** describe methodology and levels of evidence required for guideline development.

**Slides 5 & 6** DSMIG process for guideline development and reference for website for updates.

- Essential criteria for healthcare screening programs.
- A summary of SIGN/NICE procedures for evidence.

The presenter should refresh their knowledge of the criteria for guidelines by consulting the NICE and SIGN guidelines information web sites, prior to presenting this lecture, and check for any updates to the DSMIG Guidelines available on the DSMIG website.

The presenter must ensure that course participants understand the criteria for inclusion of particular items in a guideline. Not sufficient that a condition can be screened for or a test is available. Screening must be shown to have a benefit for the child and their family. See Slide3.

The final slide in this presentation reminds health professionals of their wider duty of care to children, and for which guidelines for good practice could/should be available in addition to health surveillance guidelines.

- How best to present the initial diagnosis
- Provision of support and counselling
- Identification and management of health issues
- How to make appropriate specialist referrals
- Best routes for provision of information to other agencies
- How to act as an effective advocate for the child in their care

## **Session 7**

# **System review of health-related aspects of Down syndrome**

**Session 7: System review of health-related aspects of**  
**Down syndrome**  
**Session outline**

<b>Activities</b>	<b>Time</b>	<b>Material and Resources</b>
<b>Activity 7.1</b> lecture Which conditions are specifically related to Down syndrome? Possibilities for screening will be presented.	3 hours	Power point presentation. (down syndrome health surveillance)

## Session 7: System review of health-related aspects of Down syndrome

Time: 3 hours

Each of the slides addresses key points for health surveillance. The lecturer should be very familiar with each of these issues by carefully reading the relevant sections of the Mac Keith textbook.

The conditions presented are specifically related to Down syndrome.

Students should be encouraged to make a note of:

- Possibilities for screening; facts/screening options/health benefit.
- **For each issue they should note:**
  - Why include in a surveillance program?
  - Why, what and when to test?
  - What is the health benefit?
  - How will this be audited?

The subjects we shall cover are:

- Hearing
- Vision
- Immune
- Cardiovascular
- Respiratory
- Growth/ Overweight
- Endocrine plus Sexual Health
- Hematological Disorders
- GI problems/Reflux/Coeliac/Constipation/Hirschsprung
- Renal Disorders
- Rheumatological and Orthopedic
- Skin Problems
- Dental
- Neuropsychiatry

# DAY (2)

## Day (2) Program

Time	Subject
07:30-08:00	Registration
08:00-08:15	Session 8: Day 2 Briefing
08:15-09:45	Session 9: Planning an Age-Related Surveillance System
09:45-10:15	Break
10:15 – 11:15	Group work presentation
11:15-11:30	Session 10: Developing an Interagency Model of Care
11:30-13:00	Group Activity
13:00-14:00	Presentation of Information
14:00-15:00	Lunch break

# **Session 8**

## **Briefing**

**Session 8: Briefing**  
**Session outline**

Activities	Time	Material and Resources
Activity 8.1 Briefing for Day 2	15 min	Power point slide

## Day Two - Session 8: Briefing

Time: 15 minutes

### *Activity 8.1*

#### *Briefing for Day 2:*

Course participants will be referred to the Day 2 Learning Objectives:

1. To apply knowledge revised on Day 1, and evaluate how it might be applied in the context of Oman's healthcare delivery system in the most cost-effective and efficient way.
2. In formulating a plan for Learning Objective 1, about how the needs of people with Down syndrome and their families perceived by themselves, are best met.
3. To formulate a method of evaluation of success in respect of 1 and 2 above.

Each participant will be expected to use the knowledge acquired on Day1 to plan with an allocated group of their colleagues the following;

- What health issues need to be included in a health surveillance program and why?
- How could this surveillance be incorporated into their present routine child surveillance program, and if additional health checks would be required.
- How could the health benefits to children with Down Syndrome and their families be evaluated e.g. improved /early detection of health problems, better service delivery, less travel, less anxiety for parents.

It would be helpful if the course organizer ensures that groups doing this activity work in the same locality, or have similar work patterns. It would also be helpful if there are participants from different disciplines in the same locality if they are grouped together.

**Session 9**

**Planning an Age-Related Surveillance  
System**

## Session 9: Planning an Age-Related Surveillance System

### Session Outline

Activities	Time	Materials
Activity 9.1 Group Work – Task 1	60 min	Interactive work in groups.
Activity 9.2 Group Work – Task 2	30 min	Interactive work in groups.
Activity 9.3 Group Presentation	60 min	Groups present with prepared materials.

## Session 9: Planning an Age-Related Surveillance System

Time: 150 minutes

*Group work:* Using the information given so far, each group will need to consider conditions related to at least two systems e.g. cardiovascular and neuropsychiatry (see below for system groupings).

The system groupings should not be altered. They have been grouped in this way to facilitate the task.

### *Activity 9.1*

60 minutes

#### *Group Work - Task1:*

To define which conditions require screening and which require continuing surveillance at which age groups? Identify where information from further research might aid decision-making.

Participants should review the criteria for including a topic/condition in a surveillance program. See lecture Day1.

Group activity: Consider the questions to be answered for inclusion in health surveillance for all the topics, but prioritise the development of a presentation about your 2 or 3 allocated topics to persuade others of the validity of your decision.

The group's discussion should include:

- Why they feel a particular system needs to be included, or excluded.
- How easy would it be to screen?
- At what age should screening be recommended/ be most effective.

### *Activity 9.2*

30 minutes

#### *Group Work - Task 2:*

Linked with: Audit of progress

Having agreed priority areas, from your topics, now consider in the group how the recommendations could be accommodated into the present child health surveillance

system, and whether additional checks would be required. If so when, and how, these could be done?

Are there systems are in place that will record progress, or will systems need to be designed and rolled out with the introduction of surveillance and screening?

Group activity: Design an audit form with clear outcome measures for your allocated topics.

This audit form should be designed around the existing schedule of routine child surveillance checks

Groupings of discussion topics:

Group	Topics
Group 1	<ul style="list-style-type: none"> <li>✓ Hearing</li> <li>✓ Immune/Vaccination Programme</li> <li>✓ Renal</li> </ul>
Group 2	<ul style="list-style-type: none"> <li>✓ Vision</li> <li>✓ Skin Problems</li> <li>✓ Dental</li> </ul>
Group 3	<ul style="list-style-type: none"> <li>✓ Cardiovascular/Respiratory</li> <li>✓ Neuropsychiatry</li> <li>✓ GI Problems</li> </ul>
Group 4	<ul style="list-style-type: none"> <li>✓ Growth/Overweight</li> <li>✓ Rheumatologic</li> <li>✓ Orthopaedic</li> </ul>
Group 5	<ul style="list-style-type: none"> <li>✓ Endocrine</li> <li>✓ Sexual Health</li> <li>✓ Haematological Disorders</li> </ul>

### *Activity 9.3*

60 minutes

#### *Group Presentation:*

A 10 minute presentation to justify surveillance at which age-groups for one definite condition; one not justified, and one which might be justified with further evidence.

For the definite condition they must present a clear way in which health improvement could be audited.

# **Session 10**

## **Developing an Interagency Model of Care**

## Session 10: Developing an Interagency Model of Care

### Session outline

Activities	Time	Material and Resources
<a href="#">Activity 10.1</a> Introduction with Discussion	15 min	Power point slide.
<a href="#">Activity 10.2</a> Group Work – Task 1	30 min	Interactive work in groups.
<a href="#">Activity 10.3</a> Group Work – Task 2	60 min	Interactive work in groups.
<a href="#">Activity 10.4</a> Group Presentation	60 min	Groups present with prepared materials.

## Session 10: Developing an Interagency Model of Care

Time: 2 hours 45 minutes

### *Activity 10.1*

15 minutes

#### *Introduction with Discussion:*

Introduction with general discussion on resource availability.

This session is to encourage participants to consider the child with Down Syndrome in the widest context, and how their lives can be enriched by support from other services within and outwith health, e.g. education, social care, voluntary sector support.

Recommended use of “Getting it Right for Every Child” (GIRFEC: Government of Scotland) Wellbeing Wheel slide and to assist following group activity.

### *Activity 10.2*

30 minutes

#### *Group Work – Task 1:*

Get into the five groups to address these questions:

- What types of support services are available to parents of children with Down syndrome in Oman?

Linked with:

- What do we know about therapies and how they help?

Consider input from dietetics occupational therapy, physiotherapy and speech and language therapy, sleep counsellors, psychologists.

#### *Group Activity 1:*

Identify existing resources.

Ages and stages: which agencies are most relevant and when?

This assumes health surveillance is already in place. How do they already work together? What types of input at what ages?

Should input be pro-active or reactive?

### *Activity 10.3*

60 minutes

#### *Group Work – Task 2:*

##### *Group Activity 2:*

- Construct a Care Pathway to include appropriate input from other statutory and voluntary organizations.
- Identify clear expectations and outcomes for each age and stage.
- All groups will consider each age group and stage.
- Each group will be allocated an age group stage and asked to nominate a delegate to present their conclusions.

### *Activity 10.4*

60 minutes

#### *Group Presentation:*

One from each group (not someone who has presented previously) to present their conclusions in 10 minutes. Each group to present on their pre-allocated age-group/stage:

- Birth
- Pre-school
- Primary School
- Teenage
- Transition

# DAY (3)

## Day (3) Program

Time	Subject
07:30-07:45	Registration
07:45-08:00	Session 11: Day 3 Briefing
08:00-08:40	Session 12: Review of Oman “Guideline for Medical Management of Children and Young People with Down Syndrome” Implementation of the Oman Guidelines
08:40-09:00	Session 13: Presentation on Parent Information Resources Currently Available
09:00-09:45	Session 14: Course Knowledge Assessment Test
09:45-10:00	Break
10:00-14:00	Session 15: Clinical scenarios (Course Assessment)
14:00-14:15	Session 16: Closing Remarks with Certificate Presentation
14:15 – 15:00	lunch

# **Session 11**

## **Briefing**

**Session 11: Briefing**

## **Session outline**

Activities	Time	Material and Resources
Activity 11.1 Briefing for Day 3	15 min	Power point slide

## Session 11: Briefing

Time: 15 minutes

### *Activity 11.1*

15 minute

#### *Briefing for Day 3:*

*Note: At the end of day 2 delegates will have been provided with a copy of the “Guideline for Medical Management of Children and Young People with Down Syndrome” to review prior to Day 3.*

#### *Learning Objectives:*

- Review of Oman’s ‘Guideline for Medical Management of Children And Young People with Down Syndrome’, to ensure that delegates are aware through the work on the Course that they understand the knowledge base as applied to guidelines development.
- A Plan of Action will be considered for the implementation of the Oman Guidelines and cascading of knowledge.
- Parent information resources currently available.
- Assessment of knowledge base. This will be achieved using a written Course Knowledge assessment test (see TTT Course Exam Questions document ) –

**(NOT TO BE DISCLOSED TO DELEGATES PRIOR TO THIS TIME).**

- Assessment of communication/counselling skills in a clinical context. This will combine an assessment of each delegate’s knowledge along with their counselling skills, as they will be asked at short notice to address a clinical scenario (see TTT Course Scenarios for Delegate Assessment document.

**(NOT TO BE DISCLOSED TO DELEGATES PRIOR TO THIS TIME).**

## **Session 12**

# **Review of Oman “Guideline for Medical Management of Children and Young People with Down Syndrome” and Implementation**

**Session 12: Review of Oman “Guideline for Medical Management of Children and Young People with Down Syndrome and Implementation**  
**Session outline**

Activities	Time	Material and Resources
<b>Activity 12.1</b> Review of Oman “Guideline for Medical Management of Children and Young People with Down Syndrome – Group Work	20 min	Guideline document.
<b>Activity 12.2</b> Implementation of the Guideline Group Presentation	20 min	Group presentation materials

## Session 12: Review of Oman “Guideline for Medical Management of Children and Young People with Down Syndrome and Implementation

### *Activity 12.1*

20 minutes

#### *Group Work:*

- How to effectively cascade this knowledge?
- Who needs to know?
- How will you make this happen?
- How to work with parents?
- Are there gaps in service provision, and if so what are they, and how could they be addressed?
- Are there gaps in information for professionals and parents? How could they be addressed?

#### *Group Activity:*

Break into 5 small groups to consider the content of the Guidelines.

### *Activity 12.2*

20 minutes

#### *Group Presentation:*

Feedback from groups.

**Session 13**

**Parent Information Resources Currently Available**

## **Session 13: Parent Information Resources Currently Available**

### ***Activity 13.1***

20 minutes

*Presentation on Parent Information Resources Currently Available: see Annex 1*

Power point slide: “Parent Information Resources Discussion”

*Note: please refer to the Guideline for more information.*

**Annex 1**  
**Session 13: Parent Information Resources**  
**Currently Available**

**Activity 13.1**  
**Group Discussion**

## Parent Information Resources Discussion

### Delivery of Information

Consider publication of parent information leaflets. Is this the best way to deliver information? Different methods may be required in different circumstances depending on the audience.

Other options may include health awareness sessions or routine surveillance.

### Structure of Information

Keep it simple:

- What is the medical condition? Explained in a simple way.
- Symptoms, how does it affect the child, what else could it be?
- What should parents do? How do doctors test?
- Treatments available? Prognosis?

Information should explain clearly and concisely, using accurate, evidence based information, always with consideration for the health and wellbeing of the child.

### Type of Information

Down's Syndrome Association (UK) consulted their members and their recently published health series was a reflection of those medical conditions most commonly asked about.

Consider:

- Which conditions are commonly asked about in Oman?
- Which conditions are not?
- Which conditions may have cultural sensitivities and may be required to be presented in a certain way?
- Which conditions may be subject to common beliefs or misconceptions?

**Session 14**

**Course Knowledge Assessment Test**  
**(Course Assessment)**

**Session 14: Course Knowledge Assessment Test (Course  
Assessment)**

**Session outline**

<b>Activities</b>	<b>Time</b>	<b>Material and Resources</b>
<a href="#">Activity 14.1</a> Course Knowledge Assessment Test (Course Assessment)	45 min	Assessment Test.

## Session 14: Course Knowledge Assessment Test (Course Assessment)

Time: 45 minutes

### *Activity 14.1*

45 minutes

*Course Knowledge Assessment Test (Course Assessment):*  
See test questions provided, Annex 1.

# **Annex 1**

## **Session 14: Course Knowledge Assessment Test (Course Assessment).**

### **Activity 14.1**

#### **(Assessment Test)**

## End of Course Exam questions

1. What is the most common auto-immune disorder in Down syndrome?
2. Name three risk factors for respiratory disease.
3. What additional vaccinations might be considered?
4. What aspect of Full Blood Count Assessment can mask iron deficiency anaemia in Down syndrome?
5. What gene mutation is most commonly associated with Down syndrome Leukaemias?
6. What solid tumour carries a risk of occurrence in Down syndrome?
7. At what age should a urinary tract infection be investigated in Down syndrome?
8. Which joints are most commonly affected in inflammatory arthritis in children with Down syndrome?
9. How might cranio-cervical instability present? All five pointers required.
10. Increased plaque is a major cause of periodontal disease in Down syndrome – True or false?
11. Which epilepsies are most associated with Down syndrome?
12. What are the risk factors for Moya-Moya syndrome?
13. What are the risk factors for autism in children with Down syndrome?
14. Give an example of a serious skin condition requiring prompt investigation.

15. What is the best way to test for coeliac disease in a child with Down syndrome? How would you confirm the diagnosis? Are there any issues you would identify in relation to treatment?
16. How do you measure thyroid function in children with Down syndrome? Detail the blood parameters to be measured, and method of testing.
17. Describe the abnormalities of thyroid function seen in children with Down syndrome.
18. Detail the treatment approach for:
- children under 1 year
  - and those >5 years
19. What types of diabetes are prevalent in children with Down syndrome, and detail their different causative factors?
20. How might a pre-school child with Type 1 Diabetes commonly present?
21. List the common eye problems seen in children with Down syndrome (at least 4).
22. Outline the best approach to management of proven conductive hearing loss in the pre-school child with Down syndrome?
23. List the commonest types of congenital heart anomalies seen (if possible in order of frequency).
24. List 3 symptoms possibly indicative of cardiac problems in the neonatal period. What investigations should be carried out if you don't have access to Echo-cardiography?
25. Describe at least 2 possible 'late' cardiovascular risks for older children and young people with Down syndrome?

26. List the possible symptoms and signs of Hirschsprung's disease. How would you make the definitive diagnosis?

**Session 15**  
**Case Scenarios (Course Assessment)**

## Session 15: Case Scenarios (Course Assessment)

### Session outline

Activities	Time	Material and Resources
Activity 15.1 Case Scenarios (Course Assessment)	4 hours	Case Scenarios.

## Session 15: Case Scenarios (Course Assessment)

Time: 4 hours

### *Activity 15.1*

4 hours

#### *Case Scenarios (Course Assessment):*

**5 minutes preparation time will be given after the allocation of scenarios.**

- Delegates will be assigned the scenario they are to address randomly on the day. They will, therefore, need to have good knowledge across the full range of possible topics.
- Each counseling session will last 10 minutes.
- The whole group will observe each consultation and act as ‘critical friends’ in determining whether the information shared, and the way in which this was done, was appropriate, and effective.

#### *Case Scenarios, Annex 1*

# **Annex 1**

## **Session 15: Case Scenarios (Course Assessment)**

### **Activity 15.1**

#### **Case Scenarios**

## Scenarios for Delegate Assessment

### Aim of Scenario Task

- The scenarios deliberately provide basic information so that the participant Trainee can look at the range of possible diagnoses and therefore subsequent treatment options that should be considered. This mirrors the clinical situation. It is expected that the child and family's situation will be considered, holistically, so that their social and educational settings are referenced in any plan for the child.

### Scoring will be given to reflect:

- The appropriateness of questioning used to further elucidate symptoms and signs that could be present.

(Inappropriate and poorly targeted lines of questionings will be negatively scored)

- The Trainee's ability to know what previous information and/or results will assist in the diagnostic process.
- The Trainee's ability to develop an appropriate plan for investigation of the child, and what treatment should be put in place depending on the diagnosis.
- High importance will be placed on the ability of the Trainee to communicate clear, useful, and relevant information to the parent, and if appropriate consider any ethical issues in relation to the problem presented.

My 13 year old daughter says she does not like having Down syndrome and asks me if she will always have it. What should I tell her?

Doctor do regular antibiotics weaken the immune system?

Should my child have the MMR vaccine?

My child is very sleepy in the day – what should we do?

My three year-old has repeated chest infections, what might be causing this?

My ten year-old boy has been dry at night since the age of 5 but has started wetting the bed again. Do you think it is because he is anxious?

I have heard testicular cancer is really common in boys with Down syndrome. My son is 17 years old. Should he have a scan?

Why have you done a blood test on our new baby who has Down syndrome?

We were deeply upset when we learnt that our son has Acute Lymphoblastic Leukaemia. We are worried that he will not be treated like everyone else.

My seven year-old girl has started to limp. Can you explain what might be causing it?

You are rung by an anaesthetist about to anaesthetise an 8-year old boy with appendicitis. He wants to know if the fact he has Down syndrome means he should look out for anything in particular.

I have read that children with heart disease should have antibiotics when they have dental treatment but my dentist says there is no need. I do not know what to do for the best – can you help please?

My five-year old son's behaviour is becoming unmanageable. He has frequent temper tantrums and gets very distressed. Can you help?

My 8-month old little girl has just had an EEG. The technician says it shows something like hypsarrhythmia. What does that mean? Is it bad?

My seven year old daughter keeps having episodes where her speech is slurred and she looks vacant. These last 30 seconds or so and then she is OK. They have only been there for the last three weeks. What can they be? What should we do?

My teenage son has very frequent thrush in his groins. Is this common in Down syndrome and how can I help?

My 4 month old infant is still not feeding very well. I am trying to combine breast and bottle feeds. I am worried that there is something seriously wrong.

My little boy is now 18 months old and he doesn't seem to be interested in what I say to him, or to be making any words yet.

My little girl had an AVSD corrected when she was younger. She is starting school soon and they want to know what she should be allowed to do?

My little girl who is now 6 years is really constipated. I have tried everything. Can you help?

I have been told that lots of children with Down syndrome have problems with their vision. Can you tell me more about this and what tests he should have? My son is 4.

My child has just moved into Primary 2 in main stream school. He has become very unsettled and is not sleeping well at night, and his behaviour at school is dreadful.

The nurse at school has told me that I must have my daughter immunised against HPV. How can that possibly be useful to her!

What sorts of sports activities are safe for my child? He is 10 and very active. I want him to have lots of exercise, but I want him to be safe.

The doctors spotted a cardiac malformation on my 20 week foetal scan, and now they have confirmed that the baby has a high chance of having Down syndrome.

My daughter (aged 8) has been putting on weight regularly until 2 months ago and now she has lost over 1Kg.

My baby is 6 weeks old and keeps bringing up his feeds.

What can I do to help my baby? He just seems so floppy.

Other parents say thyroid problems are very common in children with Down Syndrome. Can you tell me why, and what checks my child should have?

I have been told my baby has failed his neonatal hearing screen. What will that mean for him for the future?

My daughter is 11 and is putting on lots of weight. Will this be bad for her and what should I do?

**Session 16**

**Closing Remarks with Certificate  
Presentation**

## Session 16: Closing Remarks with Certificate Presentation

### Session outline

Activities	Time	Material and Resources
<a href="#">Activity 16.1</a> Closing Remarks with Certificate Presentation	15 min	Certificates.

## **Session 16: Closing Remarks with Certificate Presentation**

Time: 15 minutes

### ***Activity 16.1***

15 minutes

*Closing Remarks with Certificate Presentation*

# References

## References:

- 1- Guideline for Medical Management of Children And Young People with Down syndrome, First Edition, 2015