

### Challenges for nursing in caring for CF

Evolving Role of the CF nurse / ANP/nurse prescribing

Keeping abreast of new developments

Changing practice despite workload

Multidisciplinary Team

Staff shortage/Staff burnout



IT developments electronic records-electronic communication with patients and parents

## Challenges

- New challenges have arisen in diagnosis and the clinical management
- New born screening has being a game changer leading to diagnosis of asytomatic children
- Previously children presented with symptoms
- New titles CRMS CFTR-RD CF SCREEN POSITIVE CF-SPID
- New challenges in adult population
- Given the news



Parent anxiety cross infection



### Patient and parent expectations

# Compliance and burden of care





And a second problems any lease of the second problems and the second



End stage care Quality assurance-importance of Cystic fibrosis Registries

Use of clinical audits

Stratified medicines importance of clinical trials

Amalgation of 3 paediatric hospitals

Dedicated CF centres

Healthy economy- cost of care

### Thank you for your attention

#### Being a Nurse Means...

You will never be bored, You will always be frustrated, You will be surrounded by challenges, So much to do and so little time.

You will carry immense responsibility and very little authority. You will step into people's lives and you will make a difference.

Some will bless you, some will curse you. You will see people at their worst and at their best.

You will never cease to be amazed at people's capacity For love, courage, and endurance.

You will see life begin and end. You will experience resounding triumphs & devastating failures. You will cry a lot, you will laugh a lot.

You will know what it is to be human, and to be humane.