

Nurse Practitioner New Zealand Conference
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Increasing complexities for infants, children and young people receiving palliative care

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"It's funny how day by day, nothing changes. But when you look back everything is different."

-Calvin & Hobbes

Objectives

- Provide an overview of PPC
- Outline current issues and trends in PPC
- Use a case to highlight issues of transition to adult services
- What is the future of PPC

What is Pediatric Palliative Care?

Pediatric Palliative Care prevents, identifies and treats suffering in infants, children and adolescents with serious illnesses, their families, and the teams that care for them. It is appropriate at any stage of the illness, and can be provided together with disease-directed treatment.

Evolving focus of care

- Prognostic uncertainty
- Improvement of diagnosis and options for treatment and management
- Increasing use of technology
 - gastrostomy, home TPN, tracheostomy, assisted ventilation
 - Video conference for communication
 - Apps
- Immunotherapy – modulating therapies
- Gene therapy
- Deaths will still occur
- Te Wa Aroha - Advanced care planning
- Transition

Conditions seen by Starship PPC

Jan 2016 – Nov 2017

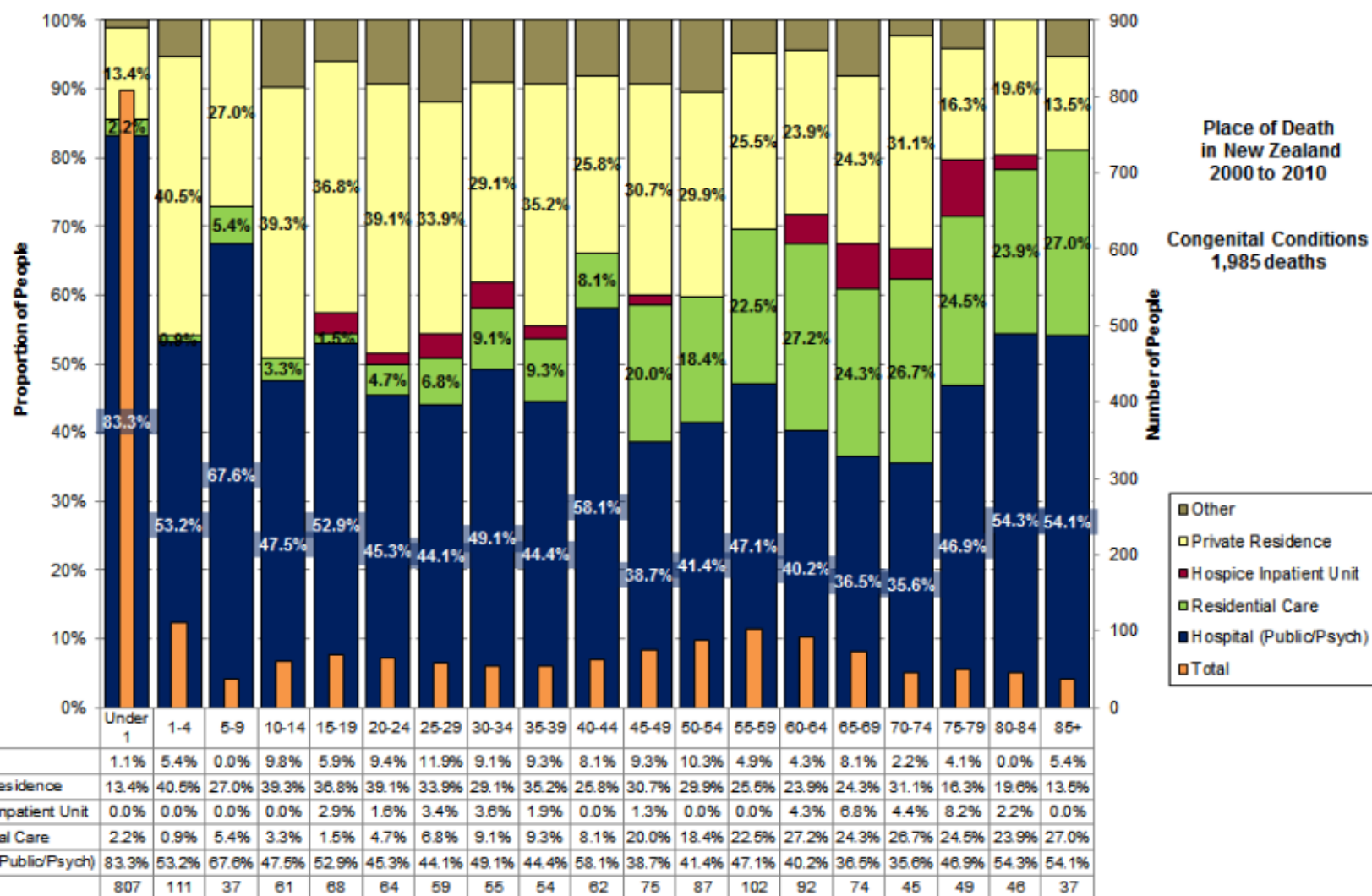
61% - Non Cancer

- Congenital/Genetic
- Neurology
- Perinatal
- Metabolic
- Cardiac
- Respiratory

39% - Cancer

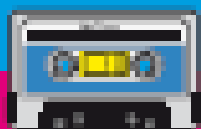
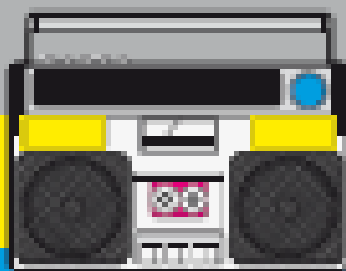
- Brain Tumours
- Relapsed Disease
- Stage IV Alveolar Rhabdomyosarcoma
- Progressive Solid Tumours
- Adverse Effects of Treatment

Congenital Deaths 2000-2010: Age



Source: Analysis of Ministry of Health MORT data 2000 to 2010

Child Poverty
in 1984
was 15%

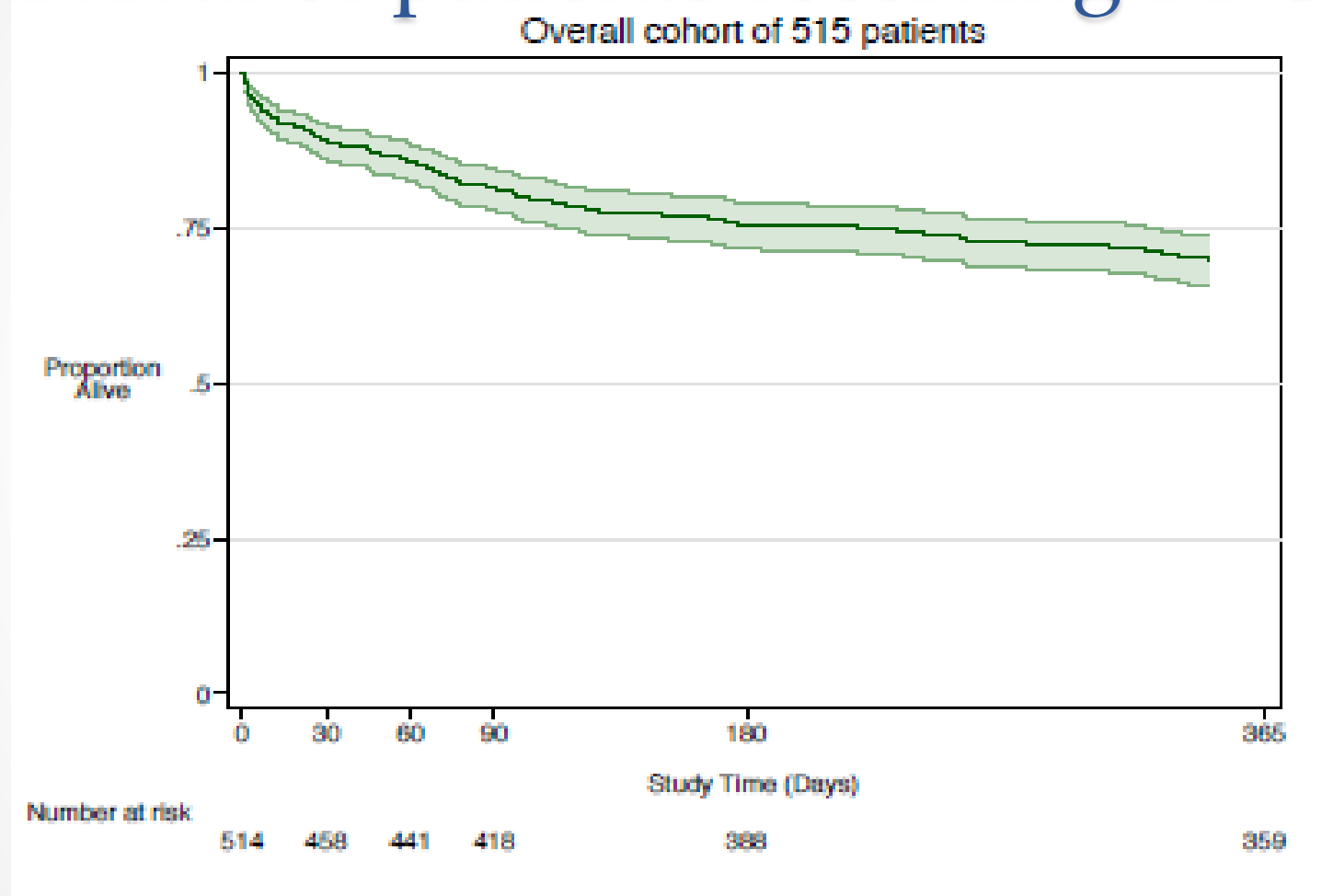


CHILD POVERTY
TODAY IS
29%

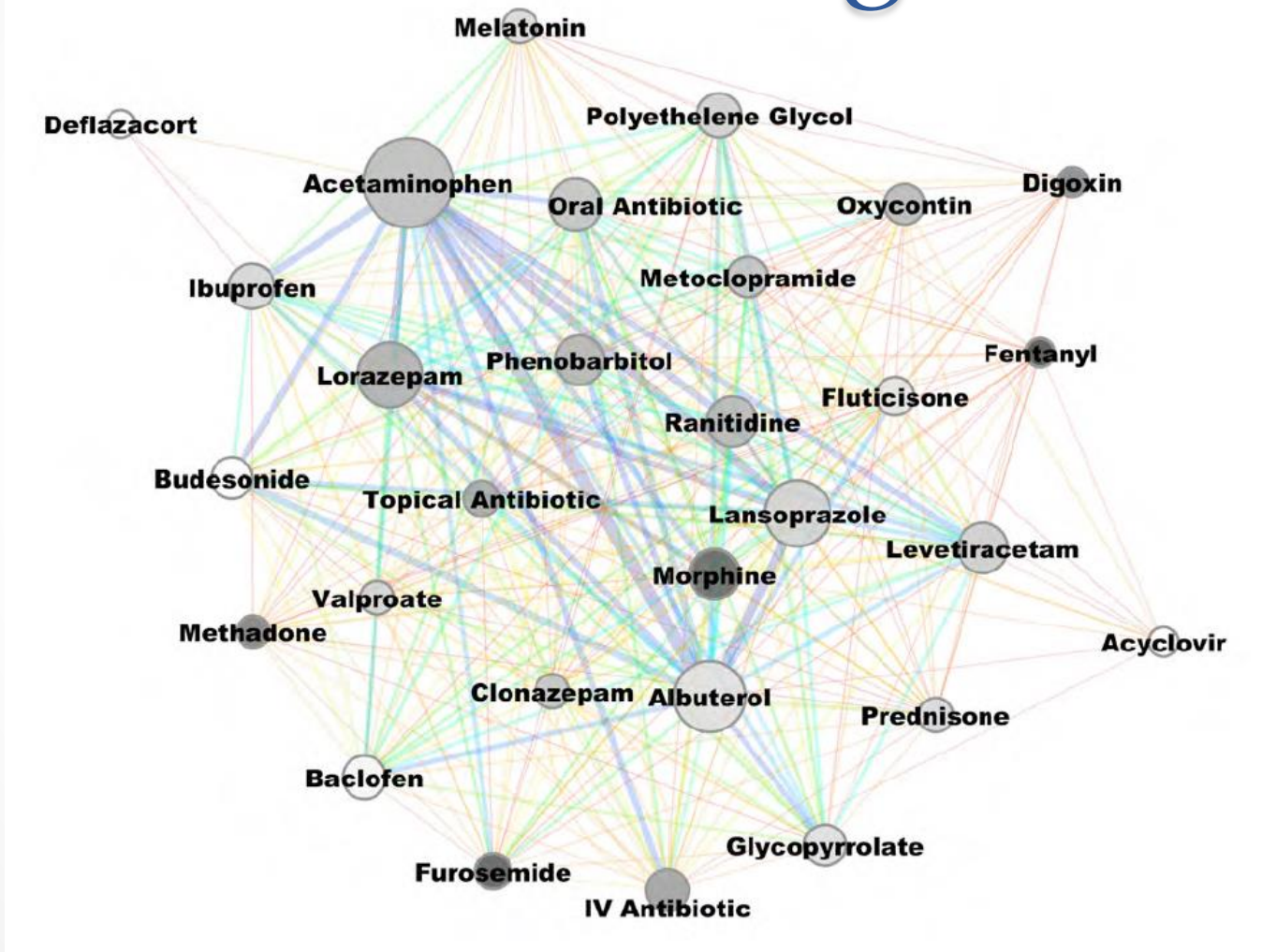
#itsnotchoice

CHILD
POVERTY
MONITOR

Survival of patients receiving PPC

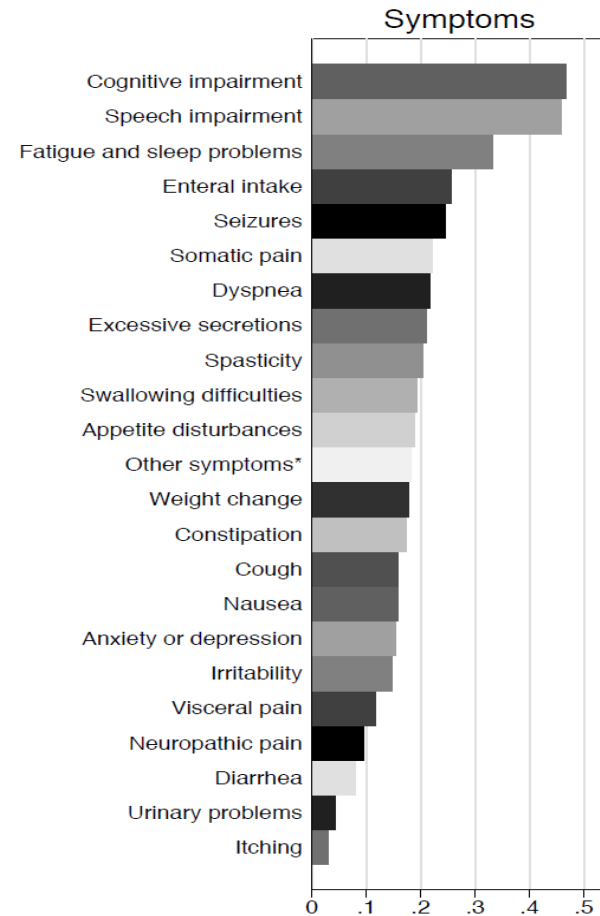


Drugs received by patients receiving PPC



Feudtner et al, Pediatrics 2011

Signs and symptoms of patients receiving PPC services



* Other symptoms include paralysis, edema, sepsis, sweating, and dry mouth.

Feudtner et al, Pediatrics 2011

Impact of pediatric palliative care

- Children with serious illnesses and their families benefit from PPC
- Earlier initiation of PPC improves symptom management & quality of life
- May lead to prolonged life

Introducing Paediatric Palliative Care – Case “J”

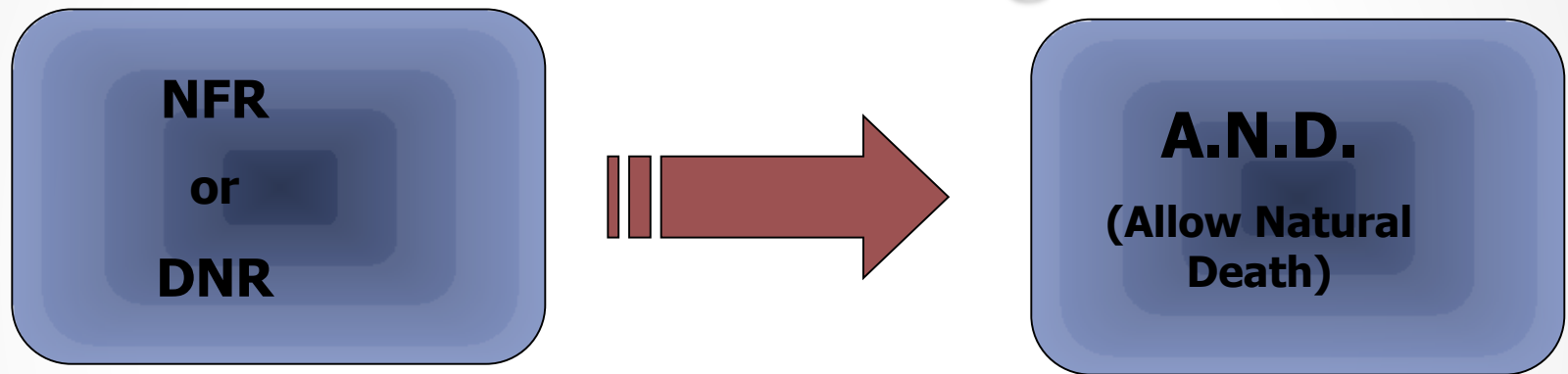
- 6 year old boy
- Maori family
- X-linked Adrenoleukodystrophy, Dx 3 yrs
- Recent progression of disease
- Role:
 - general family support
 - symptom management

Case “J”

- 5 years later
- General deterioration
- Symptoms support; admissions for pneumonia's, secretions, dyspnoea requiring oxygen at home
- Family/whanau meeting with key health professionals
- Communication & negotiation

Te Wa Aroha:

Allow Natural Death & Advanced Care Planning



- Development
- A.N.D. – focusing on what will be done versus what will not be done
- Te Wa Aroha

Case – “J”

- “J” Re-referred back to PPC, now 18 yrs old
- Transferred to adult service – back under paediatric services
- On-going deterioration however no hospital admissions for about 3 years
 - General distress, pressure areas, unsettled, breathing changes
 - Cared for by his sister, her family, his father, attends special needs school, respite Wilson Centre, Disability services, Paediatric Community Services, Metabolic Service

Children, young people and their families/whanau

- Many services involved
- May not be “one” key worker but several or one service may assume the primary role
- Increased uncertainty of trajectory and future
- Longer term impact on families
- Improvement in comfort & quality of life becomes even more paramount

Increasing numbers of AYA

- England - 2013 report
- Prevalence of life-threatening and life-limiting illnesses in young adults aged 18-40 years
- 2000-2010 prevalence increased from 26 – 34.6 per 10,000
- 33% increase

Fraser, L.F.K., Miller, M., Aldridge, J., McKinney, P.A. & Parslow, R.C. (2013) *Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010*. York: Department of Health Sciences, University of York. p189.

Goals of Transition

- Provide high quality, co-ordinated, uninterrupted
- health care that is patient-centred, age and
- developmentally appropriate and culturally competent,
- flexible, responsive and comprehensive with respect to
- all persons involved.
- Promote skills in communication, decision-making,
- assertiveness and self-care, self-determination and self advocacy.

...Goals of transition.

- Enhance the young person's sense of control and independence.
- Provide support and guidance for the parent/carer of the young person.
- To maximise life long functioning and potential.

<http://www.rch.org.au/transition/> Chambers, L. (2015) Stepping Up. Together for Short Lives; Bristol.

Transition from Paediatric to Adult Palliative Care Services

Phase One

Phase Two

Phase Three

Preparing for Adulthood & Planning Transition to Adult Services.

Goals

1. Using person centred planning approach in partnership with AYA and whanau.
2. Identify and Contact key transition services
3. Planning for transition takes place
4. The first multiagency MDT meeting takes place.

Interventions

1. The AYA needs and goals are at the centre of the transition process.
2. Individual care plan, summary letter and ACP developed to share with services.
3. Key contact for both paediatric and adult services are identified and referral made to adult palliative service as appropriate.

Preparing to Step up to Adult Services.

Goals

1. AYA supported in proactive future planning and development of partnership with adult services.
2. AYA supported to develop ACP.
3. All family including siblings to be supported and included in decision making in consultation with AYA.

Interventions

1. Utilise transition checklist.
2. Introduction to adult services.
3. Joint visits with Paediatric Palliative and Adult services including Primary care.
4. Assist AYA to develop ACP.
5. Establish decision maker in the whanau/family through whom to communicate information.

Settling in to Adult Services

Goals

1. Care and support coordinated for each AYA and whanau/family.
2. Palliative Care services provide single clinical overview for AYA and link with other services.
3. Frequent review and communication across
4. Services.
5. Strengthening of Primary Care/GP

Interventions

1. AYA has key contact in Primary and Palliative Care.
2. Ensure access to 24/7 services including Local ED, Family doctor, Specialist Palliative Services.
3. Regular review of ACP and Crisis Plans in partnership with AYA/whanau, to be distributed to all services involved.
4. Effective communication across services.

Report to the Ministry of Health

GUIDANCE FOR INTEGRATED PAEDIATRIC PALLIATIVE CARE SERVICES IN NEW ZEALAND

September 2012

Paediatric Palliative care in New Zealand – Clinical Guidelines for End-of-Life Care



Produced by the New Zealand Child & Youth Clinical Network in partnership with the Paediatric Society of New Zealand and supported by the Ministry of Health.

**Coming together is the
beginning. Keeping together
is progress.**



**Working together is
success.**

Summary

- Multidimensional
 - Wide range of services in provision of care
 - Primary, secondary, tertiary, quaternary
 - Across DHB's
- Health professional/services communication & working together
- Many services involved over many years and even into adulthood