

A ROADMAP TO AID YOU ALONG THE PWS JOURNEY (ages 0 to 36 months)
Information regarding items you may or may not encounter on your journey.

	FIRST STEP	CHILD IS 0 – 6 MONTHS	CHILD IS 7 – 12 MONTHS	CHILD IS 13 – 24 MONTHS	CHILD IS 25 – 36 MONTHS
GENERAL INFORMATION	<ul style="list-style-type: none"> • E.I.P. services • Invite to parent groups & play groups • Family's role/coping • Baby stimulation & contact • Importance of complete record keeping (eg. noting child's milestones, treatments, surgeries, etc.). 	<ul style="list-style-type: none"> • Hypotonia • Poor head control • Sucking/feeding problems & oral-motor control & stimulation(see note on feeding on back of page) • Infant massage • Variety in positioning • Bonding techniques • Family coping/ grieving/communication 	<ul style="list-style-type: none"> • Pediatric P.T. info. for facilitating gross development for sitting, prone, stretches & use of limbs • D.I.S.C. assessment • S.I. therapies • Communication/speech expectations • Importance of reading aloud to child 	<ul style="list-style-type: none"> • Pediatric P.T. info. for facilitating gross motor development for crawling & standing • Home safety • Techniques in dealing with sleep disturbance (S.I. therapy) • PWS Phase II info. • Nutrition transition • Play/sharing 	<ul style="list-style-type: none"> • Establish an active lifestyle • S.I. program if applicable • Speech frustration • Distractions from obsessions & diversion of compulsions • Food issues: home/garbage control, low-cal snacks, PWS food –foraging techniques • Skin-picking remedies • Tantruming/behavior strategies • Play/turn-taking
SERVICES INFORMATION	<ul style="list-style-type: none"> • S.C.D.R.C.D. referral • PWS Alberta, PWS USA, PWS networks & groups • Local relief services • Resources in medical community (eg. A.D.L. for feeding supplies) • Establish a good relationship with healthcare team • Parent-to-parent support groups 	<ul style="list-style-type: none"> • Rehabilitation hospital referral (ie. Glenrose & Alberta Children's Hospital) • Homecare or Pediatric rehabilitation referral for regular Pediatric P.T. & O.T. services (Pediatric P.T. for proper gross motor development sequences) • S.L.P. referral to local health centre or Pediatric rehabilitation • Genetic dietician contact through dept. of genetics • referral to a feeding clinic • E.I.P. services 	<ul style="list-style-type: none"> • See services info. from "Child is 0-6 months" • S.I. workshop (info. from E.I.P. contact) • Swimming as regular exercise • Opthamologist referral for concerns such as Strabismus • Endocrinologist referral for concerns such as Growth hormone therapy 	<ul style="list-style-type: none"> • See services info. from "Child is 0-6 months & 7-12 months" • O.T. behavior management consult through S.C.D./R.C.D. • E.N.T. or Sleep clinic specialists if sleep disturbances noted. 	<ul style="list-style-type: none"> • See services info. from "Child is 0-6 months, 7-12 months & 13-24 months" • P.U.F. info. (contact local school board for E.C.S. options). • Leisure programs in community (gym, swim & library) • Therapeutic horseback riding program • Vision therapy (upon Opthamologist's recommendation)
RECOMMENDED TOPICS TO BE RESEARCHED & MATERIALS TO USE	<ul style="list-style-type: none"> • Pamphlets regarding above services mentioned • Calendar for medical-record keeping & milestones. • PWS diagnostic criteria 	<ul style="list-style-type: none"> • Pamphlets regarding above services mentioned • Hanen speech book "It Takes Two" • PWS newsletters • books about Special- needs children • rattles/bells to Velcro to limbs, visually stimulating toys, pictures, mobiles • growth charts • Feeding info. (see note on feeding on back of page) • Nutrition info. 	<ul style="list-style-type: none"> • PWS speech difficulties • Various communication techniques (symbol, picture, sign) • S.I. info. • Sibling info. (ie. Being the sibling of a child with a disability). • Growth hormone therapy info. • Books about creative play • Appropriate level of toys & books (see your local lending library). • PWS vision info. 	<ul style="list-style-type: none"> • S.I. equipment availability • Handouts for babysitters/caregivers re food restriction & behavior management? • Toys & books (loans through E.I.P.). • PWS behavioral concerns (eg. Obsessive-compulsive disorder) 	<ul style="list-style-type: none"> • Scoliosis & PWS • PWS diet & nutrition info. for appropriate age. • PWS education/ learning strategies info. • Transition planning info. • Create a book with & about the child to aid in transitions (eg. Photos of the child's home life, favorite things, new school /program). • PWS behavioral concerns info. (eg. Tantruming).

A.D.L. Aids to daily living
D.I.S.C.
E.I.P. Early intervention program
E.N.T. Ears, nose & throat specialist

E.C.S. Early childhood services
O.T Occupational therapy
P.T. Physiotherapy
P.U.F. Program unit funding

R.C.D. Resources for children with disabilities
S.C.D. Services to children with disabilities
S.I. Sensory integration
S.L.P. Speech & language pathology

Key:

FEEDING ISSUES: KEY POINTS TO INVESTIGATE

Consult your Occupational therapist or Feeding team for the pros and cons on different feeding strategies.

Examples:

- breast feeding and breast pump alternatives
- swallowing difficulties and arousal levels
- gavage feeding and need for oral stimulation
- sucking and breathing patterns
- different shapes and sizes of nipples and soothers
- temporary use of Haberman feeder (commonly used for cleft palate).

Later:

- special cups and presentation of spoon
- biting and chewing
- textured foods
- healthy feeding routines and behaviours
- “Red, yellow, green” system – consult dietician