

# Transition of children to adult care

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Approximately 10% of young people aged 12-24 years suffer with a chronic condition, and most of these disorders will persist into adulthood<sup>1,2</sup>. The age when children are deemed to become adults, at least for health purposes, varies from country to country: the arbitrary cut-off in Malta was fourteen years but, in 2012, this was raised to a more realistic sixteen years. Nevertheless, this age is set artificially to accommodate health care practices and services and does not 'work' for all, particularly in those cases where adolescents may have associated problems of cognitive and developmental delay. A rigid cut-off and 'one-size-fits-all' transition process is unrealistic. Likewise, a totally unregulated free-for-all process that is solely decided by individual practitioners' whims is equally unworkable. A compromise position is required that respects the needs of individual adolescents, is cognizant of diverse medical conditions and differing time-frames, yet manages to accommodate all these variables within the prevailing healthcare service.

The transition process should be designed on principles established on evidence-base and best practice although, in this regard, this is often lacking or of poor quality.<sup>2-3</sup> Moreover, few countries have well developed policies on transition, and fewer still monitor outcomes of such a policy.<sup>3-4</sup> Yet inadequate or non-existent transition is associated with poor measurable outcomes such as disease control, compliance, rates of hospitalisation, patient satisfaction, and is costly.<sup>3-4</sup> Transition needs to be accessible, practical and, ultimately, serves the patient such that a potentially difficult stage in their care is both as seamless as possible and functionally effective<sup>5</sup>. The latter can translate into better (or, at least, equivalent) quality of life, compliance and disease control, as well as integration and meaningful contribution to society.<sup>1,3,5</sup>

Patients who may require long term or specialised care into adulthood should be identified as early as possible (generally by their caring paediatric team) and plans toward transition set out<sup>5,6</sup>. This can take the form of a systematic formal process that is carefully co-ordinated (by a designated lead person(s), or team), that would require planning and an appropriate set-up, such as a dedicated clinic.<sup>5-6</sup> Ideally, these would be run jointly by both paediatric and adult physicians.<sup>3</sup> Hence, for example, a child with epilepsy in Malta could be introduced into this transition set up a year or two before their sixteenth birthday, and managed jointly for the interim period. Shared care can be extended earlier, such that jointly run clinics manage children from a much earlier age. In Malta, this concept has been pioneered with significant success for children with connective tissue diseases, whereby adult physicians with an interest in childhood rheumatology were invited to set up a joint clinic within the Paediatric Outpatient Department in 2008. Indeed, this service has now been in force in Malta for over ten years, and has worked extremely well with all parties benefitting from each other's knowhow. As patients within this joint Rheumatology clinic have got older, their care has naturally migrated from the paediatric side

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toward adult colleagues. For these patients, the eventual 'final' transition at sixteen years to full adult care will be barely noticeable, with their management organised by physicians whom they have known for years. However, what works or is possible for Rheumatology where patient numbers are small, may be impractical for other specialties, and alternative options need to be found.

Any transition process needs to be individualised as much as possible, and must involve the patient and their family.<sup>5</sup> Involvement of community services and support from family practitioners and, where appropriate, NGOs is crucial to the success of this process.<sup>1,5,6</sup> Timing may depend on disease-dependent issues as well as existing healthcare services,<sup>5</sup> but later transition and in line with social changes (e.g. school leaving, or official adulthood at 18 years) may be deemed more practical.<sup>3</sup> Transition at some arbitrary, rigid time point, particularly during mid-adolescence may be detrimental.<sup>3,5</sup>

Transition clinics with the entire team present may be difficult to create and sustain – yet, to a large extent, the template for this already exists in Malta in the form of visiting consultant clinics (VCC). These have been established for more than two decades in both Paediatrics and adult domains. With a little extra organisation, part of the VCC can be allocated to transition patients who can be seen by both respective visiting and local teams simultaneously. Indeed, this has been successfully introduced for several years in the paediatric respiratory VCC, in the main focusing on adolescents with cystic fibrosis, but the model is easily transferable to other conditions. The disadvantage with VCCs is that they occur infrequently and, for some patients, a more regular review may be required. The Grown Up Congenital Heart (GUCH) Disease model 7 established in Malta is another extremely successful format of transitional care where multidisciplinary input is practiced *par excellence*. GUCH services commenced as a joint effort between paediatric and adult cardiology around 2001, and this clinic was joined by a visiting expert consultant three years later. A formal consultant post in GUCH was created in August 2015. Hence, for example, at present a pregnant twenty five year old would be managed routinely by an adult cardiologist GUCH consultant, a paediatric cardiologist with access to neonatal advice, an arrhythmia specialist if needed,

an obstetrician, and in difficult/unusual cases, a visiting cardiologist.

Similar formats already exist in Malta or could certainly be envisaged for other sub specialties such as oncology, diabetes, epilepsy, other neuromuscular conditions, inflammatory bowel disease, renal disorders, etc., etc. Some specialties (e.g. orthopaedics, ENT, ophthalmology) routinely depend on consultants to treat and follow up both adult and paediatric cases and, for these patients, transition would appear to be automatic at the doctor-level. However, this ignores other important issues related to transition such as school related versus workplace related problems,<sup>1,5,6</sup> and these need to be addressed ideally within a designated transition clinic. For the most complex and/or totally unique cases (a real possibility in a country with a paediatric population of just 80,000), a one-on-one customised hand over would be recommended. This is not difficult to achieve in a small health service where everyone knows everyone else and most work on one hospital site. In our experience, a face-to-face handover together with the adolescent and with the parents present is entirely feasible and, in general, takes just a few phone calls to organise. An alternative, whereby a ticket of referral is simply posted through the internal mail system will probably result in a non-urgent outpatient appointment in an adult clinic several months, and in some cases, more than a year down the line. In the interim, these patients are technically orphaned and will recourse to their paediatrician for support, prescriptions, form renewal, etc., with problems arising in the event of approval required for repeat visits for shared care abroad, or during a crisis requiring acute hospitalisation.

Flexibility, tolerance, respect and common sense should be the order of the day. Intransigent rigidity that results in situations whereby staff are frightened (of repercussions from higher authorities!) to take blood from a sixteen and a half year old child with Down's syndrome in Children's Outpatients or, conversely, an adult higher specialist is told off by his/her consultant for giving advice on a fourteen year old with a condition that is more common in adult patients, is totally at odds with the spirit of transition and is certainly not in the patients' interest.

An effective transition process is not an optional extra but, in accordance with authoritative

bodies and patient feedback,<sup>5,6,8</sup> should be routine practice for all adolescents with a chronic condition. It requires commitment, both at an individual physician and health service provider level, planning and focused coordination.<sup>5</sup> Malta's greatest advantage is that expert support in the form of visiting consultant clinics are already established across almost all disciplines and access to colleagues is easy. In addition, very successful 'local' models have been established for decades and these can be used to model other, new transition clinics for other conditions. Whatever the format chosen for a particular subspecialty, family involvement and patient engagement<sup>1-6</sup> together with a degree of flexibility to cater for individual patient needs,<sup>1,2,5,6</sup> are key to the success of this essential process. Every discipline could set up this service according to their own requirements, but the initiation for transition almost always starts from the paediatric side. It may, therefore, be time to consider the creation of a dedicated service with a coordinator within this specialty (e.g. along the lines of a specialist paediatric nurse practitioner) with responsibilities for transitional care.

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#### Cover Picture:

'Waterfront'

Acrylic

By Rosita Farrugia

Rosita Farrugia was born on 11th July 1952. She worked in Cardiac Lab and X-ray Dept. as a nurse. She worked in Italy with the Department of Paediatrics for 12 years in Florence and Verona.

She went for missionary work for 2 years in Kenya and 2 years in Nigeria and also to Cosovo where they took 4 containers to the Red Cross. She is also a member in the Malta Council in the Voluntary sector and she is also a member of the Fraternity of Charles de Faoucauld.