



Alder Hey Children's
NHS Foundation Trust

Alder Hey
Eaton Road
Liverpool
L12 2AP

Tel: 0151 282 4930

Our Ref: ND/ic/AH1565586

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Secretary: 0151 282 4930

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The Parent/Guardian of
Miss Gwendolyn Vials Moore
2 Coronation Drive
Crosby
Liverpool
Merseyside
L23 3BN

Department of Developmental Paediatrics

Sefton Team

PCO for Dr Daniels: Laura Macdonald

Dear Parent/Guardian of Gwendolyn Vials Moore

Gwendolyn VIALS MOORE
2 Coronation Drive
Crosby, Liverpool L23 3BN

D.O.B. 22/08/2014
Hospital No. AH1565586
NHS No. 701 057 1422

MEDICAL REPORT

Completed by Dr Daniels 12th July 2023 to be used for the purpose of updating any support plans. To be shared with professionals within health, social care and education with parental consent.

- 1. Gwen has complex medical and developmental needs requiring a high level of support and constant supervision to maintain her safety, as such appropriately trained staff and those with experience working with children with disabilities and neurodevelopmental conditions would be advisable.**
- 2. She has the following confirmed medical background:**
 - 2.1. Trisomy 21 (Down's syndrome) with associated learning difficulty
 - 2.2. Hearing impairment - history of mild to moderate hearing loss and will remain under audiology until she is 18
 - 2.3. Visual impairment - Bilateral hypermetropia & previous recurrent iritis (previous lactimal probing and syringing January 2019)
 - 2.4. Autism Spectrum Disorder (ASD) with pathological demand avoidant profile

- 2.5. Mobility problems requiring right sided osteotomy in March 2020, followed by a left patella stabilisation surgery in April 2022 and subsequent splint use and wheelchair use. Gwendolyn has permanent mobility issues, including a limp. Gwen may require further surgeries in the future and has been referred to orthotics.
- 2.6. Possible absence seizures (normal EEG 2021) and a seizure while in the burn's unit at Alder Hey
- 2.7. History of gastroesophageal reflux disease (Upper GI endoscopy and biopsies January 2019 with normal range, however, stone cobbling found to her airways, Ph and impedance study February 2021 showing evidence of minimal gastroesophageal reflux, Gwen continues daily medication).
- 2.8. Cardiac arrhythmias likely neurogenic in origin (PDA and PFO at birth, now resolved)
- 2.9. Tachy-brady Syndrome
- 2.10. Obstructive sleep apnoea (weaned off CPAP February 2019 and discharged from LTV Physio, but remains under LTV respiratory follow up with sleep study confirming mild mixed sleep disordered breathing in February 2023)
- 2.11. History of recurrent upper and lower respiratory tract infections, prophylactic antibiotics
- 2.12. Intra-capsular tonsillotomy and adenectomy
- 2.13. Isolated early menarche
- 2.14. Obesity
- 2.15. Continence - Behavioural issues with refusal to void her bladder, constipation and lack of independent skill to toilet and clean without help.
- 2.16. Obsessive behaviour with food requiring therapy
- 2.17. Recurrent fungal nail infections (especially feet)
- 2.18. Dry skin / patches of eczema

3. Medications

3.1. Omeprazole

3.2. Gaviscon

3.3. Movicol

3.4. Azithromycin

3.5. Ticonazole

3.6. Dermal 500

4. Medical follow up required:

4.1. Annual clinic review in neurodevelopmental paediatrics to include trisomy 21 health screening.

4.2. 6 monthly orthopaedic clinic

4.3. Orthotics review pending

4.4. Urology nurse led clinic pending with input from urotherapist for bladder training – 6 monthly review

4.5. CAMHS/LD specialist clinician

4.6. LTV Respiratory clinic bi-annual

4.7. Endocrinology clinic up 4-6 monthly

4.8. Optometry clinic 6-8 monthly

4.9. Audiology clinic Annual

4.10. Gastroenterology clinic 6 monthly

5. Support with health needs:

- 5.1. **Trisomy 21 (Downs Syndrome) screening** – Gwen is at increased risk of health complications of Trisomy 21 and so has condition specific screening on a yearly basis. Children with Trisomy 21 usually have an IQ in the mild to moderate low range, as well as short- and long-term memory problems. Gwen's learning needs should be identified and managed by the school.
- 5.2. **Hearing** - Gwen has a history of mild to moderate hearing loss, and has a hearing test completed annually. Gwen is inconsistent in her response to sound which is thought to now be mainly due to her concentration and attention difficulties, although her hearing can be affected by infections, etc. She would therefore benefit from prompting to maintain focus and stay on task.
- 5.3. **Vision** - Gwen has visual impairment and has worn glasses since 2018 and is under ophthalmology/orthoptics follow up regularly. She has good functioning visual fields, but the possibility raised of visual field inattention or processing difficulties which will be monitored. Gwen uses an adjusted font size and cannot read menus or basic signs, so for example, lacks the ability to distinguish a shampoo bottle from a harmful substance.
- 5.4. **Communication** - Gwen can talk using single words or short sentences but reverts to using noise and growls when distressed/for comfort. She has speech delay and is not easily understood by all. Gwen can make her basic needs known and can be very headstrong. Gwen can make a structured choice - i.e. 'this or this?', but would not be able to respond accurately to 'what would you like?' Gwen does not see animals as having feelings and frequently doesn't treat animals well. Gwen can become obsessed over things, such as 'The Grinch' and can say to people that they are not permitted to sing because she is more important, lacking any reciprocity in her interaction and failing to engage in shared enjoyment. Her non-verbal communication is challenging as she gets extremely frustrated without being able to inform adults of why, when there is a simple answer. This impacts greatly on all relationships, as her focus is object oriented and having her immediate needs met which can make for challenging interactions and impact upon relationships. Importantly, Gwen has been referred by School back to speech and language both for diction/lack of understanding and not being able to communicate that/ when she is hurt or what happened. She lacks any sense of danger and where she does not care about it- such with parents/ carer as stepping into the road and staying there because she has

been told not to. It is reported that at School she was asked to show a TA, who had returned from maternity leave her good writing and doodled instead before her 1:1 appropriately intervened. It is often reported that Gwen does not have her 'listening ears on' and is very tired. It is reported that School try to appropriately accommodate her and offer her rest/sleep and she refuses sleep even when needed.

5.5. **Mobility** – Gwen has had mobility problems from birth owing to hypotonia and hyperflexes. There are adaptations to the house and specialist equipment to aid Gwen's safe mobilisation. She regularly dislocates her joints leading to an osteotomy in 2020, which left Gwen with a significant limp. Gwen has different anatomy in a number of ways, including her bones being flat, not typically round, in profile. Gwen has turns in her feet. Gwen can walk but has always required a wheelchair for any distance. More recently Gwen required the exceptionally rare procedure of left patella stabilisation in April 2022. Subsequently she has required a plaster then splint use and wheelchair use. Prior to this, Gwen could walk around the house - slow and unsteady, but determined and generally successful in her movement, yet experiencing trips and falls every day requiring adult support to maintain her safe mobilisation. Gwen is determined to move under her own steam at home even when she was in a non-weightbearing cast. Following her surgery, Gwen was full time in a wheelchair at school and had a physiotherapy plan in place to help recover mobility. She now walks and moves, but is permanently physically disabled in respect of her walking. She is extremely slow indeed, falls and can struggle to get up without help and cannot jump at all, but she loves to dance and to be active and to 'mess with everything'. She will never walk typically due to the above difficulties and low tone associated with Trisomy 21 and still requires access to a Wheelchair. Her mobility difficulties do not mean that she could not dart into a road, causing traffic to break hard, and in fact she has done. Gwen also demonstrates impulsive behaviour and will unfasten her wheelchair straps and throw herself out without warning. Gwen is not suitable for a self-propelling/directed wheelchair due to her strength and impulsive behaviours. She currently has a bespoke Mojo wheelchair. Gwen's body can become rigid and as such she can dislocate her joints when stressed. Gwen can also be obstructive, such as standing in the road when with carers and refusing to move because it is a demand to cross the roads.

5.6. **Sensory** - Gwen does not feel or does not care about pain typically and will inflict it on herself in a sensory seeking manner and will not report it, therefore requires supervision to keep her safe from herself. Gwen has increased sensory needs

associated with autism and will play inappropriately with faeces, pick at her skin, struggles with hair washing/brushing, and has food obsession.

5.7. **GI related problems** – Gwen has reflux and constipation requiring daily medication which is given by an adult.

5.8. **Respiratory related problems** – Gwen has a history of recurrent infections for which she takes prophylactic antibiotics and has sleep apnoea.

5.9. **Sleep** – Gwen has sleep disordered breathing and experiences sleep difficulty which is common in children with neurodevelopmental conditions. Gwen requires prompts and 1:1 support to go to bed and settle to sleep. She also experiences challenge in maintaining sleep and is often awake in the early hours of the morning where again there are risks to her safety if she is unsupervised. She has woken in the night and attempted to leave the house on a number of occasions wearing only a nightie and carrying a toy shopping basket to go shopping or a backpack trolley with random items to go to Disneyland. The house is consequently secured and entries alarmed. She can also get up to cook which on one occasion this resulted in injury.

6. **Activities of daily living:**

6.1. **Personal care** - Gwen requires help with personal cares daily and this should be included in all support plans to maintain her physical health and wellbeing.

6.1.1. Gwen has an adapted bath and shower and needs assistance in getting in and out of this, as well as full assistance in washing, dressing and teeth brushing.

6.1.2. Gwen cannot make clothing choices, cannot fully dress or undress.

6.1.3. Gwen needs to be taken to the toilet, which has a supporting toilet frame, as she either has no insight into needing the toilet or refuses to go in order to avoid day to day demands placed on her, the urotherapy team meet with Gwen regularly for therapy intervention to assist her to know/be in more healthy control of her toileting. Attempts to wear a wobl watch to assist this have been unsuccessful owing to Gwen's sensory needs and a request has been made that an adult wear this in place of Gwen so that she can be reminded throughout the day of when to toilet – this is necessary at home and in school and will be put in to place at the start of next term.

- 6.1.4. Gwen experiences constipation and as stated behavioural challenge around voiding her bladder. In view of this she experiences wetting and soiling requiring full care in the toilet and with hand washing, with at least 1:1 but sometimes 2:1, due to both mobility and challenging behaviour.
- 6.1.5. Gwen will smear faeces around the house and so maintaining general hygiene for her and her family is a significant challenge. Gwen cannot clean herself after toileting effectively, she will attempt this and is consistent in soiling clothes, smearing faeces, remaining unclean and putting tissue paper into her bottom.
- 6.1.6. Gwen has experienced recent urinary tract infections which could be linked to this behaviour and so personal hygiene is essential to be maintained.
- 6.1.7. Gwen also has had early menarche and has had menstrual bleeding which complicates her personal hygiene Gwen has no capacity to tend to this herself. This requirement for care has previously led to her being kept off school and denied access to education in the past – this is not acceptable, and it is understood that the inclusion team is/has worked with School to put a policy in place to allow her to attend. The policy was never shared with parents or other provision. It is understood that Gwen no longer bleeds regularly but does bleed occasionally/ sporadically, which has not really been an issue in School.

6.2. *Eating and drinking*

- 6.2.1. Gwen will put anything in her mouth and try to eat things which are not edible.
- 6.2.2. Gwen is obsessed with food and remains under CAHMS owing to poor behaviours around food, such as drinking a teachers' drink at school and then vomiting and spoiling another child's lunch by trying to take it from them, she steals food both in home and school, and has incurred burns from attempting to steal adults' hot drinks. More recently after stealing a bite of her 1:1s sandwich, the behaviours were reported by School to parents that they had lessened. However, she went through a number of other children's School bags recently in order to try to steal food. She has also attempted to leave the house with a shopping basket to obtain food which is at great risk to her safety and therefore requires constant supervision in all spaces.
- 6.2.3. Gwen can restrict her diet through obsessing over certain foods and her preference would be to eat the same foods, rather than a wide variety of foods- being obsessed with ham and cheese. At the same time she would eat anything

someone else had and would crave it and struggle to leave others alone and not take food which is not hers.

6.2.4. Gwen is learning to eat better with a knife and fork both at home and at School.

She often shovels food at her face, and so is a messy eater and is at risk of aspiration/choking. She needs constant supervision. Gwen can drink from a cup without a lid, but almost always requires a straw, she again requires supervision with this as she will spill liquids.

6.2.5. Gwen cannot prepare any food or drink, she does not drink enough and seems to confuse thirst with hunger.

6.2.6. Gwen does not appear to ever feel full, has a food obsession, is obese and is under the care of a dietician, endocrinology and CAMHs therapy.

7. Social and behavioural support:

7.1. Gwen has complex medical and social needs. These are long standing and will require long term 'round the clock support' to ensure Gwen is safe, happy and thriving; ensuring her physical and emotional needs are met.

7.2. Any support plans in place need to take the above complexities into consideration along with her challenging behaviour profile and autism which impacts on her mood and behaviour which negatively affects her ability to access a learning environment. Given her medical complexities, Gwen attends multiple health appointments which may impact on her access to learning. Gwen has had a number of operations and her health needs are ongoing. She has required the input of community Occupational Therapy and Physiotherapy for her to be able to safely return to School. When attending medical appointments there are adaptations made at Alder Hey, for example, she was recently taken to blood clinic and refused to comply to give blood and even with restraint it was not possible to go through with the blood test. The play team / SEN team are involved with Gwen to facilitate her safe access to healthcare.

7.3. For the duration of her care under our service, she has received at least 1:1 support, rising to 2:1 support given her increasing and significant behavioural challenge in inability to maintain any self-safety. Gwen has demonstrated impulsive behaviour when outside running into the road and running into other people's houses. This

support is included in her school risk assessment and is in place when she is outside of her classroom. This limits her access to some activities such as parties and school trips where her safety cannot always be guaranteed owing to her impulsive and challenging behaviour.

7.4. Gwen has required a constant 1:1 and a low demand approach to completing the most basic of tasks.

7.5. Gwen attends a large number of hospital appointments as well as unscheduled visits when unwell, her behaviour while in hospital has required specialist input from the learning disabilities team, and sedation due to unsafe behaviours and risk of harm to herself from sensory seeking as well as impulsive behaviour. It is noted her compliance is deteriorating with age and she is becoming more demand avoidant. To maintain her safety, even with structure, at least 1:1 is required at all times.

7.6. Gwen is a child in need and has a disability Social Worker who supports the family and provides 50 hours of funding on a 2:1 basis owing to her complexity and the challenges in keeping her safe. I understand this is a long-standing arrangement and provision is shared with her sibling Isaac who also has challenging needs. Until recently, Gwen accessed Claire House Children's Hospice also on a 2:1 basis when outside the setting and a 1:1 inside at all times, again confirming her challenging behaviour and difficulty maintaining her safety. Gwen attends Aiming High provision on a 2:1 basis following their assessment of her needs. Both were already in place when Child Services undertook their last assessment and so the care provided by those services was not included in their calculation of what was needed to be funded by them.

7.7. Gwen requires consistent caring relationships which are especially important to her emotional wellbeing and enabling her to develop lasting secure relationships with peers and carers. Gwen requires a robust framework of support that caters for her needs and ensures she is empowered to reach her academic and social potential. Changes can result in school refusal.

7.8. Whilst Gwen is headstrong, she benefits from being challenged to learn/develop and maintaining a consistent and routine approach to most things in order for her to feel comfortable and have a sense of control over life and events. Even with this consistency, Gwen can display challenging behaviour which can compromise her safety and the safety of others. Escalation in challenging behaviour can be minimised/avoided by ensuring she has a consistent routine and a sense of

involvement and control over decisions. Gwen benefits from consistent support and familiar faces in her support provision.

7.9. Gwen is a loving and caring child, who can form relationships over time ensuring there is consistency, and she feels safe. Gwen can behave very well in routine and a highly structured environment with consistent support. She is headstrong and fixed in her approach to everything and therefore struggles a great deal with change that she does not understand, with demands placed on her and with unstructured environments. This necessitate her being prepared in advance for changes and a low demand approach to any request. In the hospital setting she has, for example, had her medical plans changed and adapted on the basis of lack of compliance.

7.10. As time has passed, Gwen has required more support and provision has increased in every area of her life. This is required to continue to keep her safe, happy, healthy and meeting her potential. Gwen would thrive with familiar, experienced (those with experience working with children with disabilities and neurodevelopmental conditions), and highly structured support with a low demand approach.

Yours sincerely

Electronically checked and authorised by Dr N Daniels

Dr N Daniels
Consultant Neurodevelopmental Paediatrician

Copy to:

Dr NA Tong
Blundellsands Surgery
Blundellsands
Liverpool
L23 6TZ

F Chikowore
Social Worker - Complex Needs
Social Services
3rd Floor
Magdalen House
30 Trinity Road
Bootle
L20 3NJ